

**Exploring discrepant views of the quality of life of stroke survivors:  
A means of investigating adjustment to stroke**

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## **Abstract**

**Objectives:** Reviews have suggested that stroke patients and family members frequently hold different impressions of the patient's quality of life. Understanding such differences may be particularly useful for clinicians who wish to help clients adjust to the effects of a stroke. The aim of this study was to investigate how the responses of stroke survivors and their family members differ when indicating the stroke survivors' quality of life, and whether such differences are associated with greater time elapsed since the stroke onset.

**Design and Method:** A related-subject design and a correlational design were utilised in this study. People who had suffered a stroke within five years were compared with nominated members of their family. All participants indicated the perceived quality of life of the stroke survivor using the WHOQOL-BREF. The time elapsed since their stroke was recorded and the participants' mood was assessed.

**Results:** No significant differences were found between the stroke survivors and the family members' views of the stroke survivors' quality of life. However, agreement between these groups was found to be low in the Social domain of the WHOQOL-BREF. Greater time since the stroke onset was found to correlate with greater discrepancy between groups in the Social domain, but not in the other domains.

**Conclusions:** The results suggest that families' adjustment to stroke does not conclude when improvement in function slows. Instead, a stroke continues to affect families years after the initial stroke. These findings may be interpreted within the context of quality of life response shift, where changes in the stroke survivors' evaluation of their social lives may not be identified by their families. This may reflect a common trajectory following stroke. The methodological limitations of this study and suggestions for future research are discussed.

## **Chapter 1. Introduction**

Stroke has a greater disability impact than any other chronic disease, and causes a wider range of disabilities than any other condition (Adamson, Beswick, & Ebrahim, 2004). The sudden impact of suffering a stroke may have wide-reaching effects on the patient's own physical and psychological well-being, as well as on the well-being of those family and friends who are close to the patient. After a stroke, a range of health and social care professionals are likely to be involved in improving function and ameliorating distress, and it is crucial that the nature of these effects are recognized and understood if appropriate care is to be provided.

The background and rationale for the present study will be explored in the following sections. First, the causes of stroke and the resulting physical, cognitive and psychological consequences are described, placing stroke in a national context. The concept of adjustment to chronic illness is then introduced, together with theoretical models of adjustment and a review of the current literature. Studies that are particularly related to patients' adjustment to stroke are highlighted. Then the use of the Quality of Life construct in assessing adjustment is presented. The current study aims to use discrepancies between patients' and family members' measurement of patients' Quality of Life as a means of exploring trajectories of adjustment to stroke, and the existing literature of proxy-measurement of Quality of Life is therefore evaluated. This leads to the aims and hypotheses of the present study.

### **1.1 *The national significance of stroke***

The definition of stroke provided by the World Health Organisation is “rapidly developing signs of focal (or global) disturbance of cerebral function lasting more than twenty-four hours (unless interrupted by surgery or death), with no apparent nonvascular cause” (Thorvaldsen et al., 1997, p. 210). The definition includes patients presenting with clinical symptoms suggestive of subarachnoid haemorrhage, intracerebral haemorrhage, or cerebral infarction. It should be noted that as this is a clinical definition, no medical imaging is required for a patient to meet the criteria.

Stroke has major implications for health provision in the UK. The direct cost of stroke care to the National Health Service is estimated at £2.8 billion a year, with the additional care costs borne by patients’ families estimated at a further £2.4 billion. Over two million hospital bed days are accounted for annually by stroke patients, and eleven percent of all deaths are attributed to strokes (National Audit Office, 2005). Within Scotland, it is reported that stroke care in hospitals accounts for five percent of the overall NHS budget and seven percent of NHS beds (Dennis, Flaig, & McDowall, 2008).

The implications for the carers of stroke survivors can be particularly severe. In addition to the lost income from the survivor, carer or both amounting to an estimated £1 billion per year (National Audit Office, 2005), the carer may also be required to expend a great deal of physical and emotional energy in order to provide adequate care, with the possibility of the survivor being admitted to a nursing home if they are unable to continue. Survey data collected by the Royal College of Physicians (Rudd, Hoffman, &

Irwin, 2005) indicated that 63% of carers had problems with their physical health since becoming the carer of someone who had suffered a stroke, and 56% had developed problems with their mental health.

#### 1.1.1 Incidence and prevalence of stroke

Improvements in stroke prevention and in stroke care appear to have been responsible for the steady decline in mortality from stroke over the past twenty-six years (Goldacre, Duncan, Griffith, & Rothwell, 2008). However, increased survival has led to an increased prevalence of disability following stroke. As the population ages, and as medical advances further decrease the incidence of death following a stroke, it is likely that a growing number of adults and their families will suffer the physical and emotional consequences of a stroke.

Incidence refers to the number of new stroke diagnoses occurring within a specified period. Kwan (2001) summarised a range of UK-based incidence studies, and provided a crude estimate of two first-time strokes per 1000 people in a year. Studies typically show an exponential increase in incidence with age, so that the incident rate in people aged over 85 is approximately 100 times higher than in people aged 35 to 44. Given this trend, it is unsurprising that recurrent strokes account for more of the total number of strokes in older age groups than in younger groups. One study reported that although recurrent strokes accounted for 25-35% of all strokes on average, this proportion increased to 50-70% in patients aged 75 and over (Williams, Jiang, Matchar, & Samsa, 1999).

Patterns of incidence and prevalence appear to be broadly similar across the developed world. A large study commissioned by the World Health Organisation concluded that incidence of stroke attacks was falling in 13 of the 17 countries studied for men, and 15 of the 17 countries for women (Thorvaldsen et al., 1997).

Within the Highlands of Scotland, the only local estimate of first-ever stroke incidence comes from a study by O'Neill and Godden (2005). This found an incidence of 1.1 per 1000 population, which is markedly lower than national estimates. However, at that time the Highlands stroke service had not been introduced, and many cases may have been missed by staff through lack of facilities or training. The study also showed that 42% of patients in the NHS Highland region who had a first-time stroke were living more than a sixty minute drive from a large town, while a further 20% lived at least thirty minutes away. This rurality clearly creates problems for medical services in providing timely care to patients suffering a stroke and in facilitating their rehabilitation and return to the community. However, the study suggested that while use of health and social services was low, those in the most remote regions were receiving similar levels of care to those closer to major towns.

## ***1.2 Types of stroke***

### **1.2.1 Ischemic strokes**

Strokes are typically divided into two broad categories, and the speedy classification of a case into the correct category is of critical importance. Over 80% of strokes are ischemic, where blood supply to a part of the brain is reduced. This may be due to a blockage of cerebral arteries caused by debris from the heart (cardioembolic stroke) or

hardening of the arteries (atherosclerosis), or may be due to vessels deep in the brain becoming blocked (lacunar stroke) or some other unknown condition (Adams et al., 1993). The loss of blood flow to the brain from any of these causes results in a loss of brain cell function within a few minutes, and neuron death within a few hours. Because most areas of the brain are supplied by blood from more than one source, some brain areas may die immediately, while surrounding areas are injured but may recover. These latter areas of tissue whose fate remains undecided are known as the ischemic penumbra, and they are the target for acute therapies post-stroke (Fisher & Ginsberg, 2004).

Ischemic strokes are also distinguished clinically by the Oxford Classification Scale (Bamford, 2000). This system includes Total Anterior Circulation Syndrome (TACS) where deficits in visual field, higher cortical function and sensory or motor deficits are all exhibited; Partial Anterior Circulation Syndrome (PACS), where two of the three components of the TACS are found; Lacunar Syndrome (LACS) where purely motor or sensory deficits are found; and Posterior Circulation Syndrome (POCS) where other disorders such as eye movement problems or a bilateral motor or sensory defect are found. Although broad distinctions, use of this scale has highlighted major differences in the pattern of recovery from the stroke and the chances of recurrence. For example, patients with a PACS were found to have a much higher chance of a further stroke soon after the first, while patients with POCS were more likely to have a recurrent stroke later in the first year, although they had the best chance of a good functional outcome (Bamford, Sandercock, Dennis, Warlow, & Burn, 1991).



Another class of strokes is the Transient Ischemic Attack (TIA), defined as a cerebral ischemic event lasting less than 24 hours. Typically a patient will notice some of the signs of a stroke, but these reduce completely over the course of a day, and may indicate a blockage clearing soon after its formation. For this reason, they have sometimes been considered as relatively minor incidents. However, a recent meta-analysis reported that the chance of suffering a stroke within seven days of a TIA is 5.2% (Giles & Rothwell, 2007), and current recommendations are that TIAs be assessed as soon as possible as they may provide early warning of a future stroke risk (Scottish Intercollegiate Guidelines Network, 2008).

The approximate neuron loss every hour without treatment following stroke is equivalent to that lost in 3.6 years of normal aging (Saver, 2006), and studies are increasingly suggesting that early treatment can reduce the impact of a stroke. Medicines to reduce blood clotting (such as warfarin) are often prescribed to prevent further strokes, and thrombolytic drugs that break up existing clots may be particularly effective if provided within a few hours (Wardlaw, Zoppo, Yamaguchi, & Berge, 2003). For this reason, stroke is increasingly viewed as a medical emergency, and the phrase “Time is brain” is used to highlight the importance of treating the cause of the stroke as soon as possible.

### 1.2.2 Haemorrhagic stroke

The remaining 20% of strokes are classed as haemorrhagic strokes, where blood leaks into the brain through a burst blood vessel. The leak may be in the brain itself, or within the skull but outside the brain. In either case, the result is an increase in pressure on the

brain tissue, blocking off its blood supply. There are limited treatment options available beyond surgically removing the blood and repairing the source of the leak, and the impact on the patient is often more serious than following an ischemic stroke (Scottish Intercollegiate Guidelines Network, 2008). Subarachnoid haemorrhages in particular, where the blood flows between the membranes containing the cerebrospinal fluid, are seen as the most dangerous of all strokes (Al-Shahi, White, Davenport, & Lindsay, 2006) with around half of patients dying within four weeks (Hop, Rinkel, Algra, & van Gijn, 1997). As the use of aspirin and warfarin in treating ischemic strokes also increases the chance of haemorrhage, it is particularly important that the cause is correctly identified before treatment begins.

### ***1.3 Physical and cognitive consequences of stroke***

From the admission of the patient and throughout the stages of their treatment, a wide variety of disorders and deficits may be identified. Motor deficits are common in stroke, and typically affect one side of the body only (hemiparesis). Bonita and Beaglehole (1988) found that 88% of patients showed some hemiparesis at admission. After one month this had reduced to 71% and further reduced to 62% after six months, the majority of which were mild weaknesses rather than paralysis. A recent study suggests that most of these improvements take place in the first three months, with no significant improvements found between three and six months (Verheyden et al., 2008). Fatigue is also recognised as a difficulty following stroke, and after two years a tenth of patients report that they are tired all the time, with a further quarter reporting feeling tired most of the time (Glader, Stegmayr, & Asplund, 2002).

Sensory deficits are found in around half of all patients suffering a stroke (Foulkes, Wolf, Price, Mohr, & Hier, 1988). Depending on the location of the lesion, the deficit may be in the same visual field in both eyes or a loss of vision in just one eye. Deficits of proprioception have been found in 44% of patients in one major study, with 12% showing significant spatial neglect (Smith, Akhtar, & Garraway, 1983).

Cognitive difficulties may include problems with memory, language and executive function. Anosognosia, or the denial of the existence of a deficit, has been found in 21% of patients at admission to hospital, and has a particularly poor outcome in terms of rehabilitation success (Pedersen, Jorgensen, Nakayama, Raaschou, & Olsen, 1996). The specific difficulties are expected to reflect the nature and location of the loss of blood flow, although it is reported that many patients show unexpected symptoms or fail to show symptoms that would be anticipated. This is partly due to the frequent abnormalities of blood flow in the brain. For instance, abnormalities in crucial structures of arteries such as the Circle of Willis are found in half of the population (Bowman & Giddings, 2003). To some extent, any functional component of the brain could be damaged in a stroke and many of these components are not fully understood.

A recent study of 200 stroke patients found 78% were impaired in at least one of the cognitive domains tested (Lesniak, Bak, Czepiel, Seniów, & Czlonkowska, 2008). The most frequent domains to be affected were attention (48.5%), language (27%), short-term memory (24.5%) and executive functions (18.5%). Most had substantially reduced in frequency after a year, with the exception of attention deficits which remained

common. The presence of executive dysfunction in the period immediately after the stroke was shown to be linked with poor functional recovery.

Cognitive impairment in a number of these areas is significantly correlated with increased dependent living after the acute phase (Tatemichi et al., 1994). Another study has also investigated the effect of global cognitive impairment on Quality of Life following stroke, although no link was found after controlling for variables such as aphasia and lesion size (Kwa, Limburg, & Haan, 1996).

#### ***1.4 Psychological consequences of stroke***

##### **1.4.1 Anxiety**

Anxiety usually presents as a mixture of physical and psychological symptoms. Those with anxiety may experience restlessness, irritability and increased muscle tension. They may tend to frequently worry about activities or situations, and they may therefore seek to avoid the situations that cause the most worry (American Psychiatric Association, 1994).

The prevalence of anxiety following a stroke has been estimated at around 21% (Barker-Collo, 2007), and this proportion seems to be broadly consistent among the few studies measuring anxiety. A large study in Edinburgh of stroke patients six months after stroke found 22% of patients scored more than 8 using the HADS anxiety scale (Dennis, O'Rourke, Lewis, Sharpe, & Warlow, 2000). Another study found a prevalence of Generalised Anxiety Disorder (GAD) following stroke of 27%, with a further 14% classified as worried but not fulfilling DSM-III GAD criteria (Castillo, Starkstein,

Fedoroff, Price, & Robinson, 1993). A further study by this research group found a prevalence of 19% using the newer DSM-IV criteria for GAD, and the authors suggest the difference between the two studies may have been due to the narrower criteria in the DSM-IV (Schultz, Castillo, Kosier, & Robinson, 1997). Certainly this underlines that the measure chosen to classify a psychological condition can have a marked effect on prevalence data.

In addition to generalized forms of anxiety following stroke, specific phobias are also possible in this population but may not be investigated if the measures used are not sensitive to the conditions. An Australian community study found that agoraphobia was far more prevalent than GAD among stroke patients, and this was partially obscured if the most severe psychiatric diagnosis was given precedence as instructed in the DSM-III (Burvill et al., 1995). The authors report that most of these patients had linked their fear of leaving their home to their stroke. Some were afraid of a stroke recurring while away from home, while others were afraid of being unable to cope with their stroke-related disabilities in the outside world. The degree to which they were afraid was judged as out of all proportion to the researchers' understanding of their condition.

Based on a psychiatric assessment of stroke patients according to adapted DSM-III criteria, Astrom (1996) conducted a longitudinal study of anxiety disorder following stroke or TIA. She reported that 28% were diagnosed with GAD while in hospital, although there was a high degree of co-morbidity with depression. There was a slight increase in GAD three months after stroke (31%) and the prevalence at one, two and three years after the stroke were 24%, 25% and 19% respectively. Of particular note is

the potential chronicity of GAD, as 74% of those diagnosed with GAD in the first three months retained the diagnosis for at least two years. Those with GAD also reported fewer social contacts than those without GAD, although the author notes that it is impossible to be clear whether the GAD resulted in reduced social contacts or if a limited social life is more likely to lead to GAD.

It may also be worth noting that the sudden experience of a stroke and its aftermath may be extremely traumatic for many patients. Some researchers have investigated the possibility of Post-Traumatic Stress Disorder (PTSD) playing a part in the patient's difficulties following a stroke. One study found 31% of non-severe stroke survivors had some degree of PTSD symptoms one year after their stroke (Bruggimann et al., 2006). Another study classified between 7% and 21% of patients as suffering from PTSD depending on the measure used, and found that the symptoms expressed by stroke patients were equivalent to those with PTSD without stroke (Sembi, Tarrier, O'Neill, Burns, & Faragher, 1998). The authors suggest that the anxiety response found in many patients following a stroke may be better considered as a PTSD reaction, and psychological therapies for PTSD might be considered.

#### 1.4.2 Depression

Depression has been characterised by lowered mood or a reduced interest in activities and is often accompanied by physical symptoms that may include insomnia, weight loss or loss of concentration (American Psychiatric Association, 1994). Estimates of the incidence of depression in stroke patients vary between 25% and 79% (Kneebone & Dunmore, 2000) and the discrepancies may be due to the lack of an agreed method for

measuring depression in this population (Berg, Lonnqvist, Palomaki, & Kaste, 2009; House, 1987). For example, there is some evidence that patients may not be aware of their deficits such as lowered mood, (Hibbard, Gordon, Stein, Grober, & Sliwinski, 1992), suggesting that the self-report measures validated in other conditions are not appropriate, and a clinician's judgment should be used. It could be argued, however, that the patient's experience of their mood has equal or greater validity to the opinion of a clinician.

In addition, the language and cognitive deficits that may result from a stroke can make self-report measures difficult to administer and interpret. Some authors suggest that depression should be diagnosed through systematic use of a range of sources (Gordon & Hibbard, 1997), although the substantial difficulties in implementing this may explain the limited adoption of this approach. The most recent systematic review of depression prevalence following stroke suggests that 33% of patients suffer from depression at some point after the onset of stroke (Hackett, Yapa, Parag, & Anderson, 2005), although the authors stress that this likely to be a conservative estimate because of the difficulties outlined above.

Townend et al. (2007) used a longitudinal design to investigate the changing prevalence of depression as time passes since the stroke. The authors prefer the term "Mood disorder post stroke" because of the difficulty in differentiating a transient reaction to stroke from organic depression, although it should be noted that the HADS depression scale is used as the outcome. Participants were assessed for mood disorder 2-5 days after the stroke and again at one month and three months since the stroke, and a

prevalence of 5%, 16% and 21% respectively was found. The authors also reported that this did not reflect a group of individuals with mood disorder whose numbers increased over time, but instead individuals moved in and out of the depression subset, with 50% of those categorized as mood disordered at one month moving out of this category at three months. In addition, it was reported that mood disorder was associated with some identical factors at different time points, including level of disability and social support. However, some factors were uniquely associated with a particular time point. For instance, change in impairment was significantly associated with mood disorder after one month, but not after three months. This may suggest that different processes are at work in those who are depressed at an early stage following the stroke than in a later stage. A similar study investigated the changing prevalence of depression over a 6-month period and also found the prevalence increased over time (De Wit et al., 2008). One study reported levels of depression at 55% at three years after the stroke (Lofgren, Gustafson, & Nyberg, 1999), although as the measure and procedures used were described in little detail it is difficult to be certain whether this result should be considered reliable.

As well as considering psychological conditions that occur as a result of stroke, it may be worth noting the possible psychological conditions that pre-existed the stroke. Some studies also suggest that depression may be a risk factor for stroke morbidity and mortality (Ramasubbu & Patten, 2003), suggesting that pre-existing depression may be more likely in a stroke population than might be assumed in other groups. Another possibility is that damage to certain locations in the brain may lead directly to



depression. This theory has been widely discussed in the stroke literature (Carson et al., 2000; Robinson, 2003; Vataja et al., 2001), and no decisive conclusion appears to have been reached.

The presence of depression in a stroke survivor is linked with poorer outcomes in terms of cognition, language, severe physical impairment, functional dependence and mortality (Ebrahim, Barer, & Nouri, 1987; Thomas & Lincoln, 2006; Turner-Stokes & Hassan, 2002), although whether the depression causes the poor outcomes or is due to them remains in question. It is possible that poor outcomes and depression feed each other in a vicious circle. However, studies have demonstrated that treating depression might have an effect on physical and cognitive function, and this has led to attempts to modify existing treatments for depression for a stroke population. Kneebone and Dunmore (2000) comment that while pharmacological treatments for depression have a demonstrated effectiveness in a stroke population, they also carry a risk of unpleasant side effects, discontinuation effects and compliance problems. Psychological therapies carry a much reduced risk and seem to show some general benefit (Anderson, Hackett, House, & Halteh, 2008) and there is research confirming the role of cognitions in depression following stroke (Morrison, Johnston, & Walter, 2000; Nicholl, Lincoln, Muncaster, & Thomas, 2002). However, at present there have been few studies investigating the efficacy of specific therapies such as Cognitive Behavioural Therapy (CBT), and the results of these studies have been mixed (Lincoln & Flannaghan, 2003; Nicholl et al., 2002). Laidlaw (2008) has commented that while a present-oriented

therapy such as CBT should work for patients with post stroke depression, it cannot yet be said that it does work.

## ***1.5 Adjustment to Stroke and other Chronic Illness***

### **1.5.1 Recognising and defining adjustment to a chronic illness**

In some respects, it may be easy to understand why someone may become depressed or anxious following a stroke or the diagnosis of another chronic illness, such as cancer or multiple sclerosis. What may be less easy to understand is how they can recover from the experience and perhaps integrate their ongoing illness into their understanding of themselves.

The conceptualisation and study of adjustment has not been confined to stroke patients. Researchers have investigated adjustment to specific conditions such as chronic pain (Morley, Davies, & Barton, 2005; Sutherland & Morley, 2007), blindness (Dodds et al., 1994) and various cancer subtypes (Cicero, Lo Coco, Gullo, & Lo Verso, 2009; Epping-Jordan et al., 1999) as well as approaching chronic illness in general (Pollock, 1986). No single definition of adjustment seems to have been accepted, and the terms adjustment, acceptance, adaptation and trajectory have all been used to describe a necessary process following the illness in order that the patients may function normally. Watson and colleagues (1988) define it as “the cognitive and behavioural responses the patient makes to the diagnosis” (p.203). Brennan (2001) emphasises that adjustment may not necessarily include psychological distress, but should include a disconnect with the patient’s life pre-diagnosis. He defines adjustment as “the processes of adaptation that occur over time as the individual manages, learns from and accommodates the

multitude of changes which have been precipitated by changed circumstances in their lives” (p.2).

Brennan (2001) has observed that the term adjustment is frequently referred to as a desired end-point, so that “poor adjustment” indicates the existence of depression or anxiety. He argues that the diagnosis of “Adjustment Disorder”, defined in the DSM-IV (American Psychiatric Association, 1994) as “significant emotional or behavioural symptoms in response to an identifiable psychosocial stressor or stressors” implies that such a response is to be guarded against, rather than being part of an adaptive process. This point is echoed by other researchers (Dowswell et al., 2000; Kirkevold, 2002).

#### 1.5.2 Theoretical models

While it is useful to aggregate the experience of chronic illness to provide a general model, it is also important to recognise how the different experiences may differ with different illnesses. Each illness has a distinct trajectory which may affect how the adjustment process may function. A diagnosis of cancer may be experienced after a long period of health complaints and lengthy tests, and adjustment following the diagnosis may have to incorporate adjustment to treatment, palliative care and possible death. The cancer patient may be forced to adjust to constant change. The underlying cause of chronic pain may never be satisfactorily explained or resolved, and the patient may be forced to continually convince others that the pain is real. Stroke may be one of the few conditions where onset is sudden, diagnosis is clear and some initial recovery is likely. In some respects, examining adjustment to a single stroke may demonstrate the

patients' full capacity for adjustment, uncontaminated by particular difficulties found in other conditions.

Rolland (1987) discusses and labels these distinctions, using different levels of illness onset, course, incapacitation and outcome to group health conditions into thirty-two possible psychosocial types of illness (Figure 1). Within this structure, stroke is seen as acute, constant, incapacitating and possibly fatal/shortened life span, a position it shares only with severe myocardial infarctions. He argues that this pattern leaves the patient and their surrounding family system with distinct psychological difficulties and protective factors. The acute onset may require a rapid mobilisation of resources and crisis-management skills. The constant- course of a stroke may carry a risk of exhaustion in carers and patient, but new roles can remain relatively stable. The profound incapacitation in a number of areas following a stroke may result in a particularly heavy strain on families. The uncertain outcome in the immediate period following a stroke may cause strain in the family, and the notion that "it could happen again" may lead to overprotection by the family.

		INCAPACITATING		NONINCAPACITATING	
		ACUTE	GRADUAL	ACUTE	GRADUAL
PROGRESSIVE	FATAL		Lung cancer with CNS metastases A.I.D.S. Bone marrow failure Amyotrophic lateral sclerosis	Acute leukemia Pancreatic cancer Metastatic breast cancer Malignant melanoma Lung cancer Liver cancer, etc.	Cystic fibrosis *
RELAPSING				Cancers in remission	
PROGRESSIVE	POSSIBLY FATAL		Emphysema Alzheimer's disease Multi-infarct dementia Multiple sclerosis (late) Chronic alcoholism Huntington's chorea * Scleroderma		Juvenile diabetes * Malignant hypertension Insulin dependent adult onset diabetes
RELAPSING		Angina	Early multiple sclerosis Episodic alcoholism	Sickle cell disease * Hemophilia *	Systemic lupus erythematosus *
CONSTANT		Stroke Mod/severe myocardial infarction	P.K.U. and other inborn errors of metabolism	Mild myocardial infarction Cardiac Arrhythmia	Hemodialysis treated renal failure Hodgkins disease
PROGRESSIVE	NON FATAL		Parkinson's disease Rheumatoid arthritis Osteo-arthritis		Non-insulin dependent adult onset diabetes
RELAPSING		Lumbosacral disc disease		Kidney stones Gout Migraine Seasonal allergy Asthma Epilepsy	Peptic ulcer Ulcerative colitis Chronic bronchitis Other inflam. bowel diseases Psoriasis
CONSTANT		Congenital malformations Spinal cord injury Acute blindness Acute deafness Survived severe trauma & burns Post-hypoxic syndrome	Non-progressive mental retardation Cerebral palsy	Benign Arrhythmia Congenital heart disease	Malabsorption syndromes Hyper/Hypothyroidism Pernicious anemia Controlled hypertension Controlled glaucoma

\* early

Figure 1- Categorisation of chronic illness by psychosocial type (Rolland, 1987)

Rolland also draws attention to the time phases of illness (Figure 2). Three major phases are termed the crisis, chronic and terminal stages and each carries associated tasks for the family and patient. The *crisis* phase includes any period of pre-diagnosis where symptoms are apparent but unexplained, and the initial period of coping and

readjustment following the diagnosis and treatment. The tasks will be to learn to deal with the symptoms of the illness, as well as more general goals such as creating a meaning for the illness, grieving for the pre-illness family identity and pulling together to respond to the crisis. The *chronic* phase is the period of “day-to-day living with the illness”, where the family must cope with a fairly constant strain, and the task is to maintain some degree of ‘normal’ life while coping with an ‘abnormal’ situation. Finally, the terminal phase is connected with all the feelings of grief and loss that accompany the patient’s inevitable death.

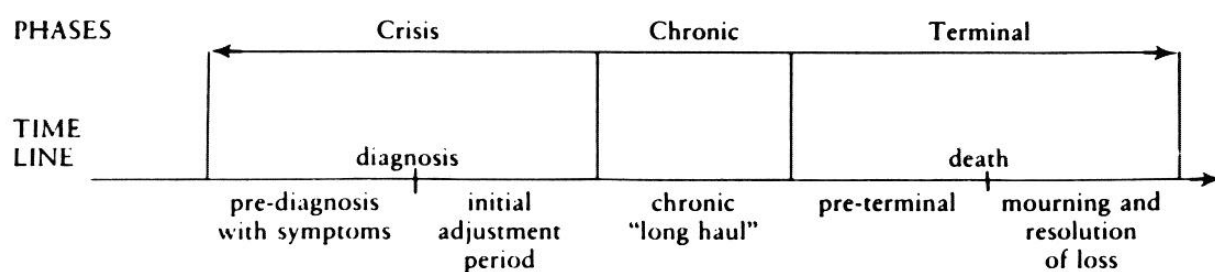


Figure 2- Rolland's phases of illness model (Rolland, 1987)

These phases may be useful in conceptualising a family’s response to a stroke. While there may be a very short period between the appearance of symptoms and the diagnosis, there is a prolonged crisis period, where a sudden change in the patient must be adapted to quickly. This may take place in the acute stroke unit of the hospital and may continue once the patient has been discharged into the care of their family. Throughout this period, patient and family may have access to a wide range of medical and social

supports in order to facilitate this process, and the patient may make some recovery. Once recovery slows and the environment has settled, the supports may disengage from the family, and this transition to the “long-haul” may be carried out in relative isolation. This chronic period may continue almost indefinitely, and the terminal phase may not particularly apply to stroke patients. However, it may be accompanied by particular strains and possible difficult feelings of relief if the patient’s death would release the family from care obligations.

While Rolland’s model provides a broad overview of the processes of illness, it may suggest a rather deterministic viewpoint- that these phases are common among all patients. The experience of illness may frequently follow the course he suggests, with the tasks and changes that are implied, but others may have a different experience of illness with an individual path. Rolland himself demonstrates that each illness has distinct features that may bring various stages of illness to the foreground, while others are reduced or eliminated. Likewise, it seems reasonable that patients and families may bring something to the experience of illness that also affects the course of adjustment.

A contrasting theory of illness is the Social-Cognitive Transition (SCT) model (Figure 3) proposed by Brennan (2001). This incorporates theories from the coping literature and the traumatic stress literature as applied to illness, and draws on Power and Dalgleish’s (1997) cognitive model of emotion. Brennan emphasizes the role of our assumptions about ourselves and the world surrounding us that reflect the accumulation of our life experience. These are seen as biologically adaptive in allowing people to make predictions, and may be understood at a conscious or pre-conscious level. When we

make a prediction based on these assumptions, they will either be confirmed or disconfirmed by subsequent experience. If the expectation is confirmed, the assumption is strengthened. If the expectation is disconfirmed, this may lead to a lengthy period of disorientation, during which time information cannot easily be processed, and stress while the assumption is adjusted to take account of the new experience. Denial and avoidance in the short-term can allow the experience to be diluted, reducing the distress and facilitating the adjustment.

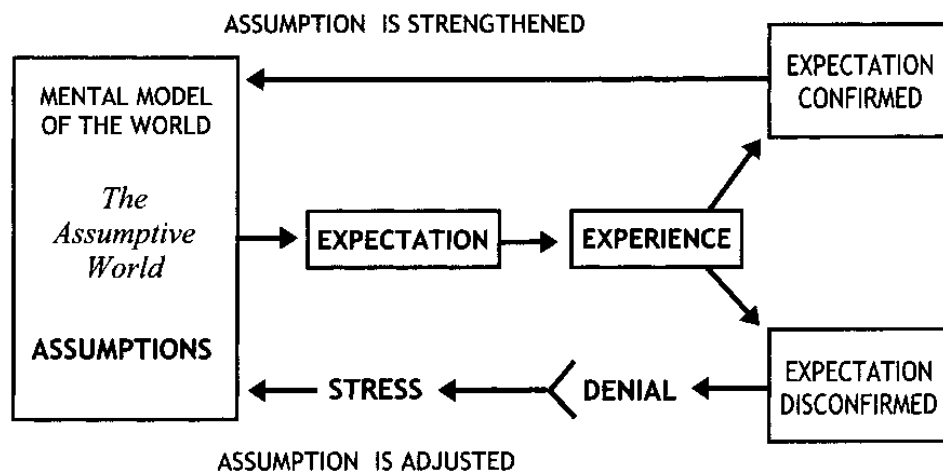


Figure 3- Social-cognitive transition model (Brennan, 2001)

This model helps explain the individual differences in responding to illness, as people will hold different assumptions, experience events in different ways mediated by social and cultural factors, and may have different characteristic ways of responding to incompatible information. Brennan goes on to hypothesise particular beliefs that may be held during cancer and the positive and negative transitions that may result from this. For example, the core assumptions for a cancer patient regarding their autonomous or



dependent attachments with others may be challenged. This could result in a positive transition for the patient, perhaps by allowing relationships to become more valued and engaged. Alternatively, a loss of valued autonomy may lead to the adoption of defenses that seem to reduce any subsequent dependency, such as withdrawal or criticism. Brennan suggests that social support provided with an emphasis on empathy may best allow the patient to have their distress contained, and the opportunity for new assumptions to be shaped. The therapist may therefore have a role in either providing this support directly in a therapeutic environment, or by assisting the patient's support network to be confident in providing it.

Brennan's model allows a broader perspective of the psychological effects of illness. A strongly-held assumption (or core-belief, or schema) that is inconsistent with the illness may be shattered by the experience, and the time to rebuild it in the face of this new evidence may be seen as the adjustment period. Meanwhile, someone with an identical illness but with different assumptions might be able to incorporate the illness into their existing assumptions, and so adjustment would be a less stressful process.

Unfortunately for the current study, Brennan's work focuses strongly on cancer, and so particular assumptions of relevance to cancer are highlighted that may not be easily applicable to stroke patients. As Rolland has highlighted, different illnesses may have much in common overall, while remaining distinct in a range of features. From Rolland's matrix of illnesses by psychosocial type (figure 1) it is clear that key differences between stroke and cancer include the nature of the onset, the course of the illness, the degree of incapacitation, and to some extent the likely outcome. The

patient's trajectory following a cancer diagnosis may be expected to contain more turbulence, with greater highs and lows, owing to the costs and benefits of the treatment. Someone with cancer may have a chance of complete recovery as well as a chance of premature death, while the patient who has survived the initial stroke may be only uncertain as to the degree of recovery. These are substantial differences, and may be sufficient to reduce the applicability of the SCT model to stroke patients.

However, the SCT model has been produced in terms that seem to allow its applicability to any illness. In essence, so long as the patient has assumptions that lead to expectations that are in turn tested by experience, it is reasonable to conclude that the same processes of denial and stress lead to an adjusted assumption in the same way. In some respects, the fluctuations that accompany a diagnosis of cancer may be expected to produce a more confused picture of adjustment, as different experiences may be contradictory. The more static stroke trajectory may allow study of the SCT model in a relatively controlled situation.

### 1.5.3 Longitudinal studies

Longitudinal methods may provide the best chance of identifying consistent patterns of adjustment to illness among patients, as they may track many individuals in the months and years after a diagnosis. The method allows researchers to eliminate many sources of error arising from cross-sectional techniques, and may allow common factors to be more effectively isolated. For example, the difficulty of transitions between hospital and community care can only be fully investigated by following patients through these processes (Cameron, Tsoi, & Marsella, 2008). Unfortunately, this approach is laborious,

time-consuming and expensive, and researchers may be reluctant to begin such a study until models have been tested in other ways. Perhaps because of the practical difficulties involved, there have been few investigations of patients' long-term response to illness over many years and even fewer studies of this nature that are specific to stroke. Those that do exist are described below, along with a selection of studies investigating a shorter period.

A Netherlands study examined the physical and psychological changes to breast cancer survivors at three time points over eight years (Schroevers, Ranchor, & Sanderman, 2006). In addition to following the survivors they compared the experimental group with age-matched cancer-free controls, thus allowing the effects of the illness to be isolated from the effects of aging. They measured depressive symptoms, anxiety, life-satisfaction, self-esteem, social resources and marital satisfaction, and tested 206 patients (from a larger initial sample of 475) at three months, fifteen months and eight years following diagnosis. Analyses revealed a significant drop in depressive symptoms between the first two timepoints, and that the level of depression was only higher than controls at the first timepoint. However, none of the other measures showed any significant change over time or difference with controls. A concurrent qualitative interview at eight years indicated that many of the cancer patients attributed positive changes of their view of themselves and their view on life to the cancer. However, healthy controls reported equivalent changes, leading the authors to suggest that such impressions may be more due to a self-enhancing cognitive bias about themselves than due to their response to cancer.

While the Netherlands study appears to be unusual in its scope and in the inclusion of healthy controls, the lengthy gaps between the selected time-points cause difficulties in linking the study to the models described previously. In addition, the controls indicated that they had experienced a similar number of chronic illnesses over the period studied, seriously reducing their distinctiveness from the experimental group. However, the study seems to suggest that some adjustment has taken place between three and fifteen months post-diagnosis, at least in terms of depressive symptoms, and that little adjustment occurs in the period after.

A study over a similar period of time using stroke patients and controls has been reported by Dam (2001), although with fewer participants and measures. Ninety-nine patients and twenty-eight controls (who had been hospital patients following a prolapsed disc) were followed up for seven years following discharge, and there was no significant difference in depression between the groups at the seven-year time-point. Depression in stroke patients was not predicted by earlier depression, family history of psychiatric illness, or the lesion site. Stroke patients reported more subjective change in emotional lability and irritability than controls, but reported similar levels of fatigue. The finding that similar levels of depression were revealed in the two groups is intriguing, although methodological difficulties may limit confidence in this result. Again, the inclusion of controls with health problems only allows the differences unique to stroke to be isolated, and does not allow features of a stroke that are similar to other health problems to be investigated. It is also worth noting that while the patients were tested at various points there was little use of this in the analysis, so the change in depression scores is not

available and the study thereby suffered many of the limitations of cross-sectional analysis. The difference in subjective impressions of the patients is an interesting result, however, and implies that the seven-year narrative of recovery from stroke has distinct features.

Longitudinal studies with stroke patients frequently reference the study by Astrom, Adolfsson and Asplund (1993), and it appears to have been the first to examine whether psychosocial and health factors might have differing relationships with psychological difficulties as time passes following a stroke. The researchers followed patients for three years following their stroke, testing them at discharge and after three months, one year, two years and three years. They found that the prevalence of depression varied considerably across the span of the study, with an initial increase after three months, a significant drop at one year, and two non-significant increases at each subsequent year (the overall increase between one and three years was significant). At discharge, the main factors discriminating between the depressed and non-depressed patients were connected with the lesion site and with the presence of dysphasia, and patients living alone were more likely to be depressed. At every other time-point, reduced social contacts were associated with depressed patients, with factors relating to cortical atrophy also discriminating at three years after discharge.

A study by King and colleagues investigated the links between depressive symptoms, physical health and coping in stroke patients (King, Shade-Zeldow, Carlson, Feldman, & Philip, 2002). Fifty-three patients were tested at the time of their discharge from hospital and at six weeks, one year and two years after discharge. Depressive symptoms were

reduced at each subsequent time-point, although only the drop between the first and last time-point scores was significant. As in the study by Townend et al. (2007), different patients obtained high scores at each time-point, with only 6% obtaining scores above the clinical cut-off at each occasion. Family functioning appeared to deteriorate across the length of the study, and the proportion of patients with dysfunctional ratings increased from 8% at discharge to 33% after two years. Increased levels of depressive symptoms at discharge were significantly predicted by limited availability of support, greater use of avoidance coping strategies and less frequent use of 'finding meaning' strategies. Two years after the discharge, the two significant predictors were family functioning and high levels of 'belonging support', or the perception that they are meaningfully connected to other people's lives. The differences between these two analyses suggest a change in what works for patients over the course of recovery. Perhaps at discharge the patient simply needs to cope with the crisis, and benefits from a coping strategy that promotes engagement with the difficulties and for this engagement to be supported. At two years, however, the lengthy period of returning to normal life has more extended challenges, and these may be better met by the patient's sense of their part in a functioning family.

The theme of families interacting with the stroke patient is the subject of investigation of a recent Swedish study (Jonsson, Lindgren, Hallstrom, Norrving, & Lindgren, 2005). The researchers compared the quality of life of stroke survivors at four and sixteen months following a stroke to that of their informal caregivers, using the SF-36 measure of Quality of Life (Ware Jr & Sherbourne, 1992). While the caregivers' scores showed

no significant change over that time, the stroke patients' scores decreased in the 'physical functioning' subscale, and increased in the subscales describing 'social functioning', 'mental health', 'role limitations due to emotional problems' and the 'mental component summary'. This seems to indicate that patients' lives improve over time in some respects, despite the difficulties due to physical problems remaining salient, while caregiver's do not see the same improvements. However, the caregivers tended to have higher Quality of Life scores in most areas, although in the areas where the patients were improving the gap had narrowed. This study demonstrates the different trajectories that may be experienced by the person whose own body has changed following the stroke and the people whose difficulties are due to changes in someone they care for. While it might be tempting to see these two groups as recovering in tandem, studies such as that reported by Jonsson and colleagues clearly suggest that there are substantial differences.

The longitudinal studies outlined above demonstrate the difficulties inherent in the methodology. The associated costs limit the number of testing occasions that can be performed, and the researchers generally must either run tests in rapid succession or allow substantial time to pass between tests. This leaves analysis either limited to relatively short-term periods, or allowing so much time to pass that results are difficult to interpret. However, the studies do support some general conclusions of long-term adjustment to stroke. Astrom et al.(1993) and King et al. (2002) demonstrate that the factors that predict depression following stroke are different at different timepoints, and both seem to suggest that social interaction becomes increasingly important as time

passes since the stroke. Schroevers et al.(2006) also seem to support a distinction between ‘acute’ and ‘chronic’ periods following illness onset, with little measurable change in depressive symptoms after the acute period. Dam (2001) finds similar results among stroke patients but finds that, while depression may have reduced, the subjective experience of patients is that problems still remain. Finally, Jonsson et al. (2005) demonstrate that the trajectories experienced by patients may not be equivalent to those experienced by their caregivers, who may be more likely to continue to focus on patients’ difficulties than the patients themselves.

#### 1.5.4 Qualitative Studies

The restrictions facing researchers who attempt to investigate stroke using quantitative techniques has often resulted in a mismatch between effort expended and results obtained. Part of the difficulty in designing a longitudinal study in particular is in knowing at the outset what you might later want to test in a few years time, and researchers have understandably tended to focus on well-examined psychological constructs such as depression. Patients may feel that important aspects of the experience of stroke recovery are missed. Some authors have commented that more is known of the psychological impact of strokes from the medical profession than from patients, and that it would be beneficial to aim for balance between the perspectives (Anderson, 1993).

An alternative approach is to allow patients to tell their own stories of stroke recovery, and use the techniques of qualitative analysis to draw common themes from these narratives. This strategy may be particularly useful in understanding the context surrounding patients, and perhaps particularly so when exploring a multi-factor concept



such as adjustment. Dowswell et al. comment that “while standardised measures may be useful to measure capacity, they do not indicate the circumstances in which patients will or will not carry out these activities or indeed the importance of that specific activity for the person concerned” (2000, p. 514)

Dowswell et al. (2000) produced their own qualitative study of how stroke patients assess their recovery. They conducted semi-structured interviews with both patients and caregivers at between 13 and 16 months after the stroke. They reported that participants all discussed the impact of their stroke in relation to their life before stroke. One caregiver commented that the impact had been “like a balloon bursting. Everything’s gone...all your plans, everything you were going to do” (p.510). The enforced changes in role for both patient and caregiver were frequently linked with feelings of frustration and helplessness. Some said they would like to be ‘their old selves’ and found it difficult to reconcile the gap between their ambition and their expected recovery. Patients struggled to accept the slow rate of recovery at this stage, and the researchers commented that there seemed to be “a big difference between being a temporary burden on the household and becoming a permanent burden” (p.513). Some patients were particularly upset that they were “ruining the lives” (p.512) of their family members. A few patients appeared to have “arrived at a sort of truce with themselves”, although the researchers commented that while this might be seen as a successful adjustment, it appeared to be of quite a different quality to lack of depression. One such patient said “If I wake up in the morning, very good luck to me. If I don’t, I couldn’t care less” (p.513). The researchers concluded that patients’ views of their own adjustment were

constantly made in reference to their life before the stroke, rather than the progress made so far, and that an idea of ‘successful adjustment’ might be more akin to a “realistic pessimism” than “blithe over-optimism” (p.514). The study provides a rather negative impression of recovery from the patient’s perspective, and while it should be borne in mind that the study focussed on a single point in time following the stroke, it is worth noting that this was around the time where Astrom et al. (1993) found the lowest prevalence of depression among patients.

It is also possible to gain material over time in a qualitative study. Kirkevold (2002) used a series of interviews with nine patients over the first year after their stroke, and aimed to describe a common trajectory following stroke. Four phases were described. The first responses shortly after the stroke (at the ‘Trajectory onset phase’) were given with relatively little emotional content or tone, and there is a sense that the stroke may be a ‘short-term intermission’ in the patient’s life. The body is seen as the main focus for adjustment, and responsibility for this is largely given to the healthcare team. ‘Initial rehabilitation’, describes the next phase which lasts as long as the patient remains in the hospital, and is characterised by hard work to recover function and an initial attempt to make sense of the stroke. At this stage, life is seen as on hold while recovery is pursued. After discharge, the patient enters a phase of ‘Continued rehabilitation’ which is increasingly self-directed. The patients describe the experience as both exhilarating and depressing, depending on whether a goal is reached or missed. The expected timescale is gradually extended, as it becomes clear that improvements are slight despite the hard work. The ‘Semi-stable phase’ begins when improvements in function are slight, and

assistance from professionals gradually disappears. Focus shifts towards the aspects of life that are of most importance to the patient, and the task is one of amending and substituting old activities that can no longer be performed.

Kirkevold's study can be seen as supporting much of the theoretical work outlined earlier. The description of four phases may be seen as expanding Rolland's (1987) stages of illness, with the crisis stage being roughly equivalent to the trajectory onset phase and the beginning of the initial rehabilitation phase, and the chronic stage encompassing both the continued rehabilitation and semi-stable phases. There are also many examples of slow incorporation of new experience that do not fit with past experience, as described by Brennan (2001). It may be assumed that further reflections on the process by the participants might be possible as months and years increase and that further changes may take place.

The importance of social relationships following a stroke has also been investigated using qualitative methodology. Lynch and colleagues (2008) discussed various aspects of life since stroke with distinct patient and caregiver focus groups and found that patients tended to spontaneously introduce factors relating to social relationships into the discussion. The researchers concluded that these areas were of particular importance to the patients. One of the interesting findings of this study was that the areas that caregivers saw as contributing the greatest impact on the patient's quality of life, such as role changes, were rarely mentioned and given little significance by the patients. Conversely, while communication difficulties were seen as having lasting importance to patients, caregivers tended not to view such difficulties as a major concern. These

differences of opinion may be important in understanding the changing relationships following stroke, as will be described further in this introduction. Caregivers also reported that patients wanted to believe their lives had not been affected by the stroke, and therefore refused to acknowledge many of their limitations. Patients tended to refer to their physical difficulties as challenges they had worked to overcome and only rarely referred to barriers that were still limiting their activities. As this study included patients who had suffered a stroke between two and eleven years previously, these results seem to reflect patient impressions of the impact of their stroke some considerable time after the acute stroke period. Patients were recruited by responding to flyers posted in healthcare settings, and it may be that the few patients who responded are not representative of the stroke population.

These studies together suggest that an idealised goal of recovery may not be appropriate for many stroke patients. Instead, the studies suggest that the path of adjustment is one that continues to present challenges to patients and their families and a conclusion may never be reached. Kirkevold suggests that the semi-stable phase achieved towards the end of the first year allows patients to explore other important areas of their lives and replace activities that are no longer feasible. The longer-term patients interviewed by Lynch seem to report that these tasks may still be active, and differences in perspective between patient and caregiver may become more pronounced.

#### 1.5.5 Impact of the stroke on the family

While the majority of the illness recovery literature focuses on the patient (Wellard, 1998), there is increasing awareness that the family's role in providing support requires

a parallel adjustment. Families frequently take on the caregiver role and prevent the patient being removed from their home, supporting the patient and aiding their rehabilitation. Their tasks may involve providing emotional support, managing reduced finances and responding to any challenging behaviour from the patient, all of which are viewed by caregivers as difficult and time-consuming (Bakas, Austin, Jessup, Williams, & Oberst, 2004). The cost of looking after their family member may be paid for in their own mental health and well-being. The prevalence of depression in family caregivers has been variously estimated as 30%, 42% (Anderson, Linto, & Stewart-Wynne, 1995) and 33% (Berg, Palomaki, Lonnqvist, Lehtihalmes, & Kaste, 2005) depending on the measure used. Berg and colleagues also noted that prevalence of depression among spouses of stroke survivors was significantly higher (38%) than caregivers who were not spouses (19%), although this difference narrowed over time.

A recent literature search has been reported by Green and King (2007) into the recovery trajectory of men who had suffered a minor stroke and their female caregivers. They found that few studies investigated this topic, but were able to conclude from existing studies that difficult role changes and slow recoveries had a negative effect on marital relationships. They also highlight the sudden change in status as support from the hospital terminates and as recovery slows at around six months after the stroke. They found that many reported difficulties were not apparent until some time after the stroke, including a difficulty in regaining independence and in re-establishing a sense of self. It is interesting to speculate whether the recovery trajectories of men with a minor stroke are similar to those of men with more severe strokes, or to women who suffer a stroke of

any severity. The authors note that those with minor strokes will receive relatively little support following discharge, as they are expected to recover without difficulty, and their findings indicate that their needs may be underestimated. This might suggest that a patient with a severe stroke could have their needs constantly evaluated and addressed, and their trajectory may therefore be less difficult. The scope of the review was apparently chosen to reflect the cultural norm of females providing the caregiving role in a family, as well as the reality of men typically suffering strokes at a younger age than women. By evaluating the trajectories of a tightly-defined subgroup of the stroke population, Green and King may have posed more questions than they are able to answer.

Studies investigating the role of the family in stroke tend to view the family either as a valuable source of support that may be tapped or as a part of the previous life that is also vulnerable to damage after a stroke. Evans and colleagues note that both of these may need to be considered together when assessing families as there can be positive and negative effects (Evans, Hendricks, Haselkorn, Bishop, & Baldwin, 1992). They also point out that the elements of apparent dysfunction in families may not necessarily produce negative results overall. For example, families that are high in anxiety have been shown to be caring for patients with reduced depression (Evans, Noonan, Bishop, & Hendricks, 1989), possibly because when anxiety is directed constructively the patient may be presented with more options for activities than might otherwise be the case.

A longitudinal study by Clark and Smith (1999) included family functioning as one of its variables. Family functioning was found to be one of the most important predictors

of Activities of Daily Living (ADL) scores, a measure of the activities regularly performed by the patient. Interestingly, it did not predict the activities that the patient is able to do, suggesting that the effect of a functioning family is to increase the repertoire of the patient's meaningful activities, rather than increase their ability. The authors do not speculate on the reasons for this, but it may be that the functioning family is aware of what is meaningful to the patient, and encourages the patient to focus on those activities that are meaningful. These may not be the activities where improvement is most likely, but may be the activities where small improvements confer the most benefit.

Reviews of studies such as those described above typically repeat the finding that providing caregiving for a family member following a stroke is frequently associated with stress or depression in the caregiver, and that these may have a further negative impact on the patient's recovery and well-being (Han & Haley, 1999). However, it is also clear that a family that is able to provide effective support without burning out is a valuable resource in terms of encouraging functional recovery and positively influencing the patient's psychological health (Johnson, Bakas, & Williams, 2007; Low, Payne, & Roderick, 1999). A range of interventions has therefore been designed to try and reduce the distress experienced by the caregivers. In reviewing these, Visser-Meily and colleagues isolated four distinct types of intervention, including counselling, psycho-education, specialist services and social support (Visser-Meily, van Heugten, Post, Schepers, & Lindeman, 2005). Counselling interventions appeared the most effective, although they were also by far the most time consuming, while there was little evidence to suggest that social support had positive outcomes. Interventions for caregivers that

aimed to increase their understanding did not necessarily reduce their distress, and it may be worth investigating interventions which include both caregiver and patient.

Some reviewers of the literature have suggested that studies investigating the dynamics between family members and stroke survivors over time are needed, as these might suggest different interventions at different points after the stroke (Han & Haley, 1999; Rolland, 1994). In another review, Ell (1996) provided a list of the questions that studies have neglected and remain unanswered. This included “What are the interactive effects of family members’ individual coping styles on health outcomes?” and further specifies the need to investigate “the extent to which responses among family members or marital partners are congruent or incongruent” (p.177). This broadly describes what is aimed for in the current study.

Some attempts have previously been made to investigate changing perceptions of physical ability over the time following a stroke. Knapp and Hewison (1999) looked at the measurement of disability by patients and their carers up to twelve months after hospital discharge, and found that the carers consistently rated the patients as more disabled over this time period. The extent of this disagreement was unaffected by the mood scores of either caregiver or patient. However there have been few attempts to investigate different views of psychological factors. The focus of the current study is discrepancy between patient and family member on Quality of Life measures.

### ***1.6 Quality of Life following stroke***

The concept of Quality of Life (QoL) may be particularly useful in trying to understand the adjustment process following stroke, as it relies on the patient’s subjective measures



of the satisfaction their current life brings them. Relying on the individuals' personal views of their situation may be more useful to patients than objective measures of disability, and the constructs of depression and anxiety are perhaps more concerned with abnormal functioning than in the processes of normal functioning. Few studies have investigated QoL in stroke patients in the months and years following stroke.

#### 1.6.1 Definition and measures

While the concept of QoL can feel intuitive to grasp, there has been a great deal of discussion of how it should be defined and operationalised in measures. Initially, QoL was understood by economists as being indicated by objective measures such as wealth or health status, while social scientists claimed that the subjective experience of life quality was of more importance. Cummins (2000) argued that both were valid, noting that the relationship between objective and subjective measures appears to be stronger at lower levels of objective well-being, and grows wider as objective well-being improves. This suggests that while a person's basic needs are not met, their subjective sense of their Quality of Life will be closely tied to increases and decreases in objective indicators. When these increase to the level that their basic needs are met, the person's subjective QoL will part company from objective measures, and be based on a range of other factors. In the context of illness and health-related QoL, it therefore makes sense to consider both objective and subjective measures of QoL.

This is reflected in a broad definition of health-related QoL as “the physical, psychological, and social aspects of life that may be affected by changes in health states” (Williams, Weinberger, Harris, Clark, & Biller, 1999, p. 1362), although it may be

noticed that the aspects of life in question are not specified. The WHOQOL group (1998b) defined QoL as “individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” (p.1570). The reference to expectations in this definition may link the concept with Brennan’s SCT model described earlier. A person’s quality of life may be increased by either improving their position in life, or by altering their expectations, goals and standards.

Some approaches to measurement ask global questions of the participant, allowing them to weigh up the aspects of life themselves. For example, a single question such as “How is your Quality of Life?” may be asked, along with a scale from one to ten to allow the participant to respond (Guyatt, Feeny, & Patrick, 1993). This approach may be extended so that a series of global questions are asked and an aggregate response obtained, as in the Satisfaction With Life Scale (Pavot & Diener, 1993). Such approaches are quite distinct from methods that ask participants to consider named domains of their lives. These might include health, socioeconomic, spiritual and family domains (as in King, 1996) or physical health, psychological health, social relationships and environment domains (The WHOQOL Group, 1998a, 1998b). Sometimes these areas are rated for both satisfaction and importance, and satisfaction scores for each domain are weighted for importance. Correlations between global and domain measures of QoL tend to be low, and some researchers have suggested that the practice of weighting domains sacrifices some psychometric properties for greater face validity (Trauer & Mackinnon,

2001). However, there is some evidence that the inclusion of weighting by importance adds little harm (Bernhard, Lowy, Mathys, Herrmann, & Hurny, 2004).

Considering the effect of stroke on QoL in the context of these definitions, it is clear that the concept may envelop a range of factors that are affected following a stroke. There is a clear effect on physical health, and there is evidence that psychological health is also affected. These may lead to negative changes in economic status and social relationships, and the effect on spiritual factors may be complex. However, if QoL is considered as an appraisal of the individual's situation relative to their goals, expectations, standards and concerns, part of the impact of stroke may be that these reference points are also altered.

#### 1.6.2 Response shift

Recently, a new concept of “response shift” has been introduced into the QoL literature, defined as “changes in the meaning of one's self-evaluation of QOL resulting from changes in internal standards, values, or conceptualization” (Sprangers & Schwartz, 1999, p. 1507). This concept has been used to help explain the stability of measures of QoL over time despite increasing disability, either because respondents measure their life-domains using a changing scale, the relative importance of the domains shift, or the whole meaning of the domains has changed for them. It has been argued that response shifts are a part of the adjustment process to illness, allowing patients to accept the difficulties that are imposed on them with relative equanimity (Sharpe, Butow, Smith, McConnell, & Clarke, 2005). Patients may begin to focus on aspects of life that are less

distressing. However, it is also possible that response shifts can be negative, where focus shifts towards the aspects of life that cause the most distress.

Discrepancies between objective or physician estimates of function and patient's QoL scores has been attributed to response shift in at least one study (Daltroy, Larson, Eaton, Phillips, & Liang, 1999). While the authors suggest that this may invalidate some measures of disability, it might also be said that such measures more accurately reflect the experience of the patient.

One cross-sectional study compared patients with less than 6 months since their stroke and greater than 6 months using the Reintegration to Normal Living Index (Bethoux, Calmels, & Gautheron, 1999). It found that while levels of disability were similar in each group, some of the QoL domains measured were significantly lower in the later group, particularly in relation to indoor mobility, self-care, and relationships. These domains might therefore be considered to be susceptible to a reduction in QoL, even when disability is not a factor. Unfortunately, the study has a range of methodological issues that make interpretation of the results more difficult. As disability generally reduces to some degree in the 3-6 months after a stroke, the fact that disability levels in each group were similar may suggest that the groups were not representative of the population. As the groups were of small number, systematic differences between the groups may have been present but may not have attained significance.

An investigation by Ahmed and colleagues revealed that stroke patients were evaluating their health in a different way as time passed since stroke (Ahmed, Mayo, Wood-

Dauphinee, Hanley, & Cohen, 2004). Participants indicated their QoL shortly after their stroke, at six weeks and at twenty four weeks, and at the later occasions also indicated their estimated QoL for the earlier sessions. It was therefore possible to compare stroke patients' 'now' judgments at the time versus retrospective 'then' judgments of QoL. The patients' 'now' QoL scores did not change between 6 and 24 weeks, but they retrospectively indicated that their QoL had improved in that period. Interestingly, the control group used in this study consisted of the caregivers of patients with stroke, and no significant difference between 'now' and 'then' measures of QoL was found. This may suggest that a different response in caregivers could lead to a mounting discrepancy between patient and caregiver indications of QoL. However, the control group was not evaluated at the same time-points as the patient group, and they were referring to their own QoL rather than the patients. Although the present study will not use the same methodology, evidence of discrepancy in QoL ratings between patient and carer currently under investigation might be explained by a similar process.

Other evidence does not support the existence of response shift following stroke. An ambitious follow-up study by many of the same researchers attempted to use confirmatory factor analysis techniques to find evidence of response shift in patients in the six months following stroke (Ahmed et al., 2005). If response shift had taken place, different models would have been a better fit at different time-points. This was not found, although the authors comment that a number of measurement and recruitment issues may have influenced this result. In any case, the study focused on change in the first six months following stroke, and results from the longitudinal studies previously

described suggest that adjustment may continue past this stage, perhaps in a manner more akin to response shift.

### 1.6.3 Family proxy assessments of Quality of Life

The use of family members as proxies in studies of QoL following stroke has enabled many patients to be included whose disabilities prevent communication (de Haan, Limburg, Van der Meulen, Jacobs, & Aaronson, 1995; Sneeuw, Aaronson, de Haan, & Limburg, 1997). Since these patients may be among the most in need of assistance, this practice has clear benefits for our understanding of stroke outcomes and the effective treatment of these patients. However, it is essential that family members provide responses that are extremely close to the patient's own experience, or it cannot be said that the patient's QoL is truly being measured. While physical symptoms may be equally observed by both patient and family member, the internal meaning of these symptoms to the patient may be less apparent to the outside world, and the proxy will be required to imagine life from the patient's perspective (Addington-Hall & Kalra, 2001).

Within the stroke literature and in the wider QoL literature, studies have investigated the validity of proxy use. An extensive review of proxies in QoL measurement in patients with chronic illness has been described by Sneeuw, Sprangers, & Aaronson (2002), including a range of illness types and of types of proxies. They found a general rule that significant others reported lower levels of functioning, health and QoL, while reporting higher levels of symptoms than the patients. This seems to amount to proxies having a more negative perception of the patient's wellbeing than the patient. The authors use the benchmarks set out by Landis and Koch (1977) to determine whether the strength of

agreement may be described as poor ( $<.40$ ), moderate (.41-.60), good (.61-.80) or excellent (.81-1.00), and concluded that most measure showed moderate to good agreement, viewing this as acceptable for most purposes. It may be worth noting that these benchmarks were intended for agreement between nominal categories rather than the ordinal or ratio measurement found in most measures, and Landis and Koch commented that the proposed levels were arbitrary. The positive conclusions reached by Sneeuw et al (2002) might be best seen as one interpretation of ambiguous data, and an alternative conclusion that any systematic bias is worrying might also have some validity.

Sneeuw et al.(1997) reported a moderate level of bias in proxies six months after a stroke, although this level of bias was seen as acceptable in the context of conducting useful research. Proxies consistently reported a higher impact of stroke on QoL than the patients, but the authors commented that as the proxy judgements were responsive to changes in function, their validity was supported. It is worth considering whether a valid QoL measure need be responsive to changes in function. The literature on response shift would seem to suggest that a measure could demonstrate its validity by being somewhat independent of changes in function.

The measurement of QoL in aphasic patients has been investigated by Cruice and colleagues (Cruice, Worrall, Hickson, & Murison, 2005) who compared responses from aphasic patients with proxy-responses from a friend or family member. Using a global measure of QoL the researchers found that proxies rated patient's QoL significantly lower than the patients did, with a moderate effect size. Participants also completed the

SF-36 measure (Ware Jr & Sherbourne, 1992) which comprises eight domains of QoL, and analysis of this revealed that the General Health, Body Pain, Physical Functioning, Vitality and Mental Health subscales also showed proxy respondents had reported significantly lower scores than the patients. The effect size of the General Health subscale was particularly large at 1.24, suggesting that the differences between patient and their proxy are substantial and may have a critical clinical significance. While this research presents a persuasive case for caution in the use of QoL measures with this population, it does not seek the psychosocial mechanisms that led to this result. Potentially useful information was collected, but did not seem to be used. For example, although the time since the patients' strokes ranged from 10 to 108 months, this factor was not included in the analyses.

The differences found in studies where family members answer on behalf of the patient may be partially explained by the different concerns of patient and family member. Carlsson and colleagues (Carlsson, Forsberg-Wärleby, Möller, & Blomstrand, 2007) investigated the life satisfaction of 56 patients and their partners one year after the stroke. Scores were dichotomised to indicate 'satisfied' versus 'not satisfied', and in most domains of life satisfaction it was found that a greater proportion of partners were satisfied than were the patients. This difference was significant when comparing 'satisfaction with their life as a whole' and 'satisfaction with their ability in self-care'. If partners are aware that the patient is less satisfied with their lives, this may lead them to exaggerate the degree of dissatisfaction when acting as their proxy. However, the patients were significantly more satisfied with their relationship with their partners, with



22% of couples indicating that the patient was satisfied while the partner was not. This may reflect the changing nature of the relationship for both parties, where the patient relies on their partner to continue a normal life at the expense of their partner's normal life.

A longitudinal study by Pickard et al.(2004) compared patient and proxy responses before discharge and six months following discharge. They found that disagreements between patients and proxies reduced at six months, and smaller discrepancies were found on global measures. A contradictory result was obtained by another study, finding that there was significant disagreement at three months (Williams et al., 2006). These studies used different measures of stroke and different methods of analysis. Much may depend on the types of questions being asked, as the latter study found greater differences in questions relating to psychological variables than in more objective physical variables. In either case, it is possible that as the process of adjustment to stroke continues after six months, discrepancies may be more or less apparent at a later date. Both studies suggest that future work is needed to clarify the effect of time elapsed since the stroke on proxy agreement.

## **1.7 Research aim, questions and hypotheses**

### 1.7.1 Research aim

The main aim of this study is to investigate whether patients' quality of life is interpreted differently by family members, and whether such differences change over time. The existence of such a change would provide support for theories of continued adjustment to illness. Understanding the typical recovery trajectories may assist clinicians in identifying the patients and families who may struggle in the future, and may suggest interventions to assist them. In addition, increased knowledge of the differences between patient and family member estimates of patients' QoL may be useful in researching and assisting patients who are unable to respond for themselves.

### 1.7.2 Research questions

**Do discrepancies between perceptions of Quality of Life between family member and patients change over the time since stroke?**

As patients adjust to changes in their life after a stroke, they may gradually change how they evaluate the quality of their life. The trajectory of this adjustment may not always be in step with the adjustment of the family, and may lead to increasing discrepancies between patient and family estimates of the patient's Quality of Life. This study will investigate patient and family member dyads that are at different time-points since stroke onset.

- Hypothesis 1. It is hypothesised that the discrepancy between patient and family member's perceptions of the patient's Quality of Life will be significantly higher at longer lengths of time since stroke onset.

**Do patients and their family members have different perceptions of the patients' Quality of Life?**

Family members may be a useful source of information for researchers and physicians when the patient is unable to communicate effectively, but differences between these proxy responses and the patient's responses need to be understood if their use is to be effective. This study will compare patient and family member perceptions of Quality of Life.

- Hypothesis 2. It is hypothesised that patients and family members will have significantly different scores on the measure of patients' Quality of Life.

## **Chapter 2. Method**

### **2.1 Design**

The study utilized a related-subjects design and a correlational design. Dyad participants were comprised of one stroke survivor and one of their family members. Hypothesis one was tested using a correlational design, where the dependant variables were the time elapsed since stroke and the discrepancy between the two ratings in the dyad of the stroke survivors' quality of life. This design was used to reveal relationships between quality of life discrepancy and time elapsed since stroke. Hypothesis two used a related-design where the independent variable was participant type, either stroke survivor or family member, and the dependant variable was the rating of the survivor's quality of life. The purpose of this design was to allow the examination of dyad differences in the assessment of the survivor's quality of life.

### **2.2 Participants**

#### **2.2.1 Inclusion and exclusion criteria**

Stroke survivor participants had to satisfy a set of inclusion and exclusion criteria. They had to live in the region covered by NHS Highland, be able to give written consent, and have a family member aged 18 or over who was also willing to take part. They must have suffered only one stroke within the last five years. Individuals with communication difficulties could be included if they could provide informed consent, understand questions and indicate a response by pointing. Individuals who had a

transient ischemic attack or suffered a stroke more than five years ago were excluded from the study, as were those with significant cognitive impairment.. The criteria were provided in written form to the NHS employees and CHSS staff who were expected to be seeing appropriate patients, with contact details of the main researcher in case they had any questions. No referred individuals were excluded based on these criteria, although it is likely that some individuals were not referred on the basis of the criteria.

### 2.2.2 Stroke survivor participants

Twenty individuals who had experienced a stroke in the past five years were recruited from the local health and community stroke services within the Highland region of Scotland. The researcher approached members of the Acute Stroke Unit at Raigmore Hospital, Inverness and the Chest Heart and Stroke Scotland Highland Branch, and explained the rationale and the proposed design of the study. It was agreed that patients receiving treatment by the stroke unit ward, outpatient clinics and community rehabilitation teams could be approached by the NHS Highland employee providing the patient's care, and patients in contact with CHSS could be approached by a CHSS nurse or coordinator. The patients were provided with prepared information about the study and their proposed involvement, and were asked to return the consent form using a stamped, addressed envelope provided. Twenty participants returned the consent form.

### 2.2.3 Family member participants

Stroke survivors who agreed to participate in the study were asked to nominate a family member to participate also. They were asked to nominate a family member "who knows

you well”, and these also completed consent forms. There were therefore twenty family members recruited to the study.

### **2.3 Measures**

All stroke survivor participants were asked to complete four self-report measures on one occasion only. These included:

- The Six-item Cognitive Impairment Test (6-CIT) (appendix 1)
- A demographic questionnaire (appendix 2)
- World Health Organisation Quality of Life Short Measure (WHOQOL-BREF) (appendix 4)
- Hospital Anxiety and Depression Scale (HADS) (appendix 6)

All family member participants were asked to complete three self-report measures on one occasion only. These included:

- A demographic questionnaire (appendix 3)
- Proxy-version of World Health Organisation Quality of Life Short Measure (WHOQOLBref) (appendix 5)
- Hospital Anxiety and Depression Scale (HADS)

Although the WHOQOLBref is essentially the same measure as is provided to the stroke survivors, the family members were asked to respond on behalf of their relative when completing this questionnaire.

Further details of all these measures follow.

### 2.3.1 Demographic Questionnaire

All participants were requested to complete a short questionnaire recording demographic information, including gender, date of birth, marital status, living arrangements, occupation and educational attainment. In addition, they were asked to indicate the nature of their relationship with the other person filling in the questionnaire and indicate the quality of that relationship. Participants were asked to indicate whether or not they had suffered a stroke, and the month and year of the stroke if applicable.

In order to gain a subjective impression of their overall level of disability, stroke survivors were also presented with the question “How disabled do you currently feel yourself to be?”, and an 11-point visual analogue scale with ‘0’ labelled “Not at all disabled” and ‘10’ labelled “Completely disabled”. The same scale was presented to the family members with the question adapted to “How disabled do you currently feel your family member to be?”

### 2.3.2 World Health Organisation Quality of Life Short Measure (WHOQoL-Bref)

The WHOQOL-Bref is a widely used measure of the participant’s Quality of Life. It stems from the World Health Organisation Quality of Life Assessment, or the WHOQOL100, which was developed by an international group with the aim of producing a reliable and valid measure of Quality of Life that could be used cross-culturally (The WHOQOL Group, 1998b). The WHOQOL-Bref was designed as an abbreviated version of the WHOQOL100 using data from the same cross-cultural trial

and is a 26-item measure (The WHOQOL Group, 1998a). Each item includes a question of facet of the participant's life, followed by five response options. The participant is initially asked to answer while keeping in mind their standards, hopes, pleasures and concerns, and is asked to think about their life in the last four weeks.

Like the WHOQOL100, responses from the WHOQOL-Bref are used to calculate scores in four domains of Quality of Life. The domains are Physical Health, Psychological Health, Social Relationships and Environment. Other domains had been included initially, but confirmatory factor analyses suggested these represented the best model for the data. The WHOQOL100 had used a total of 24 facets of these domains, and four items were used for each facet. In the WHOQOL-Bref, each facet was represented by one item, with the remaining two items serving as benchmark single items of overall quality of life and overall physical health. Three questions are reverse scored, and the scores for each domain are summed to provide a total score for the domain. These scores are transformed to a score between 0 and 100 to allow comparison between domains, with the higher numbers indicating greater Quality of Life. These transformations are carried out according to the instructions detailed in the WHOQoL-Bref manual (World Health Organisation, 1996).

While recognising that the reduced length of the WHOQoL-Bref compared with the full WHOQoL100 makes it particularly appropriate for patients with poor health or with impaired concentration, one study has suggested some loss of sensitivity in the social domain (O'Carroll, Smith, Couston, Cossar, & Hayes, 2000). However, extensive analysis by Skevington and colleagues (Skevington, Lotfy, & O'Connell, 2004) found



favourable results in its item-response distributions, internal consistency reliability, discriminant validity and construct validity. They concluded that, when considered on its own merits, the items and domains of the WHOQOL-Bref have satisfactory reliability and validity.

In order to compare the estimation of Quality of Life of stroke survivors by the survivors themselves and their family members, it was necessary to adapt the WHOQOL-Bref for use as a proxy-measure. The wording of each item was changed to relate to a family member rather than to the participant. These adjustments were evaluated for clarity by administering the measure on two male adults known to the researcher, aged 65 and 71, and inviting comments. This resulted in a few minor alterations to avoid lengthy sentences.

The WHOQOL-Bref has been used to measure QoL in a range of recent stroke studies, including with stroke patients and caregivers immediately after discharge (Adams, 2003), at one year following their stroke (Kwok et al., 2006), stroke patients suffering long-term pain (Widar, Ahlstrom, & Ek, 2004) and aphasic patients (Ross & Wertz, 2002). It has also been used to measure QoL in the spouses of stroke patients (Wilz & Barskova, 2007).

The psychometric properties of the WHOQOL-BREF were described in detail by Skevington and colleagues (2004). The internal reliability of the subscales using Cronbach's  $\alpha$  were reported as 0.82 for the Physical health domain, 0.81 for the Psychological domain, 0.68 for the Social domain and 0.80 for the Environment domain.

In assessing discriminant validity, the subscales were all found to significantly discriminate between sick and well populations. All domains were found to strongly correlate with a single-item QoL measure, supporting the measure's criterion validity, and no items were found to correlate more with another domain than their own.

### 2.3.3 Hospital Anxiety and Depression Scale (HADS)

The HADS was originally designed to assist assessment of depression and anxiety in hospital outpatients (Zigmond & Snaith, 1983). The self-report scale includes 14 items, where 7 items relate to symptoms of anxiety and 7 items relate to symptoms of depression. Each item has a choice of four responses which are scored between 0 and 3, with higher scores indicating increased symptom severity. The final score for each subscale is obtained by summing the 7 subscale items. Respondents are requested to indicate their response by considering the past week.

A key feature of the HADS compared to other measures of depression and anxiety is the emphasis on cognitive and emotional symptoms, rather than on somatic symptoms. This reduces the risk of responding due to states of a physical illness rather than psychological symptoms, making it particularly useful when measuring depression or anxiety in populations who are likely to exhibit physical symptoms due to illness. The brevity of the measure is also helpful in such populations, as is the ease of administration.

The use of the HADS in hospital and primary care has also been supported by an extensive literature review which demonstrated good psychometric properties, with a

cut-off score of 8 for both subscales providing the optimum balance of sensitivity and specificity (Bjelland, Dahl, Haug, & Neckelmann, 2002). The HADS has been found to possess adequate construct validity and perform satisfactorily in stroke patient populations (Johnston, Pollard, & Hennessey, 2000; O'Rourke, MacHale, Signorini, & Dennis, 1998) and has been used as a key measure in many studies of stroke patients (for example, Dennis et al., 2000; Dorman, Waddell, Slattery, Dennis, & Sandercock, 1997b; Townend et al., 2007). It has also been used to measure depression and anxiety in the caregivers of stroke patients (McCullagh, Brigstocke, Donaldson, & Kalra, 2005). A review of many HADS studies has found a mean Cronbach's  $\alpha$  of 0.82 for the Depression subscale and 0.83 for the Anxiety subscale (Bjelland et al., 2002).

#### 2.3.4 The Six-item Cognitive Impairment Test (6-CIT)

The 6-CIT (Katzman et al., 1983), also known as the Short Orientation-Memory-Concentration Test (SOMCT), was developed as an abbreviation of the 26-item Blessed Information-Memory-Concentration Scale (BIMC; Blessed, Tomlinson, & Roth, 1968). It asks the participant to provide the year, month and approximate time of day, to count backwards from 20 to 1, to name the months of the year in reverse order and to repeat and recall a short memory phrase. Responses are scored by number of errors made and a score of 8 or above has been found to indicate probable cognitive impairment (Brooke & Bullock, 1999).

Despite the brevity of the 6-CIT, it has been found to both detect the presence of cognitive impairment and discern the severity (Davis, Morris, & Grant, 1990). The 6-CIT has been found to correlate highly with the more widely-used Mini-Mental State

Exam (MMSE; Folstein, Folstein, & McHugh, 1975), but is more sensitive to mild dementia (Brooke & Bullock, 1999). The use of the measure as a screening tool for cognitive impairment is enhanced by the minimal demand it places on patients, as well as being easy to administer. Cronbach's alpha for this measure has been reported as 0.83 (Leshner & Whelihan, 1986).

## **2.4 Procedure**

The following section provides sufficient procedural details to allow a replication of the study, as well as outlining the steps taken in addressing the main ethical issues.

### 2.4.1 Research Protocol

Before designing the experiment, the researcher met with members of the Acute Stroke Unit in Raigmore Hospital, Inverness and members of Chest, Heart and Stroke Scotland (CHSS) to discuss the purpose of the project, seek suggestions and encourage their involvement. The key suggestions were that interviews with stroke patients should be as straightforward as possible and that the questionnaires be administered as interviews. The exclusion of those patients with significant communication or cognitive difficulties was discussed and it was agreed that the steps that would be necessary to allow their involvement would be beyond the scope of this study. A draft protocol was developed following these discussions and sent to the organisations for comment. This resulted in minor amendments to the information sheets and consent forms, and both organisations expressed their willingness to be involved in the project. This support was felt to be essential to the execution of the study.

Information packs for patients and their family members were assembled. These included:

- An invitation letter from either the Stroke Unit consultant physician or the Director of Advice and Support (Highland Region) of CHSS (appendix 7);
- An envelope addressed to “Stroke survivor”, containing an information sheet (appendix 8) and consent form (appendix 9);
- An envelope addressed to “Family member”, containing an information sheet (appendix 10) and consent form (appendix 9);
- A stamped addressed envelope to allow the return of consent forms.

Information packs with the appropriate invitation letters were provided to members of the Stroke Unit and CHSS for distribution, along with a description of the inclusion and exclusion criteria. They were reminded to refer any questions about the study to the researcher, and to contact the researcher if they wanted guidance over patient suitability or if they required further information packs. The packs were distributed as follows: fifteen information packs were provided to each of the four CHSS nurses and coordinators; thirty packs were provided to the manager of the Acute Stroke Unit; thirty packs were provided to the Community Rehabilitation Teams attached to the Stroke Unit; fifteen packs were provided to the other professionals attached to the Stroke Unit. Fifteen more information packs were provided to one of the Community Rehabilitation Teams after they indicated that they had distributed them all. A total of 120 information packs were therefore distributed. All groups participating in the study were contacted at

regular intervals to ensure there were no difficulties in referring, that the criteria were understood and that they had sufficient information packs.

Consent forms received by the researcher included a contact telephone number for each participant. The researcher used this to contact the patient, explain his association with the study and arrange an appropriate time and venue for the interviews. Participants were all given the option of being interviewed at home or at a local hospital or clinic. The procedure for the interviews was outlined to them, and they were reminded that they were entitled to withdraw from the study at any time without consequence.

On arriving for the interview, participants were reminded that the interviews would be carried out in private, and if both participants were present it was agreed who would be first. The participant was first presented with the demographic questionnaire, then the 6-CIT, then the WHOQoL-Bref, and finally presented with the HADS. Participants were then thanked for their time and asked if they would like to receive a summary of results when these were available, in which case their address was recorded separately.

#### 2.4.2 Ethical Approval

The North of Scotland Research Ethics Committee granted ethical approval for the study on 9<sup>th</sup> March 2009 (appendix 11). The study was also approved by the Ethics Committee of the Edinburgh University Clinical Psychology Department.

The main ethical issues were considered to be potential distress to participants, heightened scores for anxiety and depression, confidentiality and informed consent. These areas were individually addressed to ensure that the study conforms to the ethical

standards required by the University of Edinburgh, the NHS and the British Psychological Society.

#### 2.4.3 Potential distress to participants

It was not expected that completing the questionnaires would cause participants distress. However, it was acknowledged that the process of completing the questionnaires could raise certain issues for some of the individuals participating in this study. This possibility was addressed by providing all participants with contact details for the researcher who was able to offer support and advice and discuss any issues, either directly after participation or by telephone. Participants were also advised in the information sheet, during the telephone call and at the interview that they could stop completing the questionnaires at any time if they became distressed.

#### 2.4.4 Heightened scores of anxiety and depression

It was possible that patients or their family members could have shown elevated scores on the depression or anxiety questionnaires and may not have been currently receiving treatment for these. All participants were therefore reminded be reminded that if anything in the questionnaires highlighted any issues for them then they would have the opportunity to discuss this with the researcher. The researcher would then offer suggestions as to how professional support might be obtained, with a discussion with their GP as the most immediate step. In the event of discovering an individual has elevated scores of anxiety and/or depression on the HADS (indicated by a score of more than 11) the researcher informed the participant of his concern and suggested that the

participant obtain support. This was left up to the patient, although contact details for the researcher were left in case they wished to discuss this further.

#### 2.4.5 Confidentiality

All data connected with the study is stored in locked cabinets within the Department of Psychological Services, New Craigs, Inverness. All identifiable information relating to participants has remained on the consent forms, and a code is used to identify individual patients. The consent forms and list of identification numbers are stored separately from the questionnaires. No identifiable information was entered onto the statistics program or any other database.

#### 2.4.6 Informed consent

A key component of our inclusion criteria was that participants must be able to provide informed consent. When working with stroke patients there is a wide range in this ability, and communication and cognitive difficulties frequently cause problems. The referrers to the study were instructed that those patients who would not be able to understand or retain the information necessary to give informed consent would not be suitable. Likewise, patients who would be unable to effectively communicate their decision would not be suitable for referral. This measure does limit both the potential number of participants and the generalisability of the results, but it was felt that alternatives to this would unnecessarily diminish the participants' rights and be difficult to administrate.



Those who did participate had provided written informed consent prior to participating. Participants were repeatedly reminded of their right to withdraw from the study, and were encouraged to discuss their involvement with others before making a decision.

#### 2.4.7 Sample size estimation

Necessary sample sizes were estimated using the SamplePower software (Borenstein, Rothstein, & Cohen, 2000). Sneeuw and colleagues (2002) found differences between patients and family members of small and medium effect sizes in a range of QoL measures, but commented that effects of this size are unlikely to be of clinical significance and were therefore acceptable. Therefore, an effect size of 0.8 (a 'large' effect size according to classification system in Cohen, 1992) was sought. To detect this with a power of 0.92 and an alpha level of 0.05, twenty pairs of participants were required. In order to reveal a correlation of 0.6 (a 'good agreement' according to the classification system in Sneeuw et al., 1997) with a power of .89, a sample size of 20 was required. In order to reveal a correlation of 0.4 (a 'moderate agreement') with a power of .91, a sample size of 60 was required. It was decided that a good agreement would be of sufficient clinical use and that obtaining the higher sample size would be unlikely in the Highlands, because of both limited referrals and significant travel time. In this study, 20 participants were obtained in both the stroke survivor group and in the family member group.

## **Chapter 3. Results and Analysis**

The descriptive statistics relating to the sample are presented first, followed by the investigation of the main hypotheses of the study. All analysis of data was performed using the SPSS statistics package ("SPSS for Windows," 2005). Analysis was undertaken using parametric methods where appropriate assumptions were met. Data analysis was guided by the aims and hypotheses of the study and therefore not all possible comparisons are made, although additional post-hoc analyses are provided where further investigation seemed appropriate.

### ***3.1 Analytical Strategy***

Paired t-tests were used to identify any differences between responses by the stroke survivors and their family members on the primary measures, where assumptions did not depart from the assumptions of equal variance and normality (Howell, 2007). As the sample sizes are equal, most statistics manuals suggest that the test is fairly robust for heterogeneity of variance. Sani and Todman (2006) suggest that, unless the variance of one sample is more than four times the variance of the other, parametric tests are likely to be adequate. This was checked for all comparisons, and variances were found to be within that boundary unless otherwise stated in the text.

There are a number of tests for non-normality to select from, although recent evidence suggests that the Shapiro-Wilk test is far more likely to detect true deviations from normality than the more frequently cited one-sample Kolmogorov-Smirnov test,

particularly when the sample size is small (Mendes & Pala, 2003). The Shapiro-Wilk test was therefore used to determine if a distribution of scores differed significantly from normality. When a significant difference was found, the Wilcoxon Signed Ranks test was used. Unless stated in the text, the data met the assumption of normality. Finally, in order for parametric tests to be justified, data should be of either interval or ratio levels. Most of the tests used in this study produce ordinal level ratings: that is, a higher number only indicates that it is “greater than” the previous score, without indicating how large the difference between scores is. However, when a number of such scores are summed, the resulting data is often viewed as being greater than ordinal level, and therefore parametric statistics can be justified (Sani & Todman, 2006). Parametric tests have therefore been used where ordinal data is summed in this study, while non-parametric tests will be used where single ordinal items are tested.

Pearson correlation coefficients were used to identify any relationships between the variable “Time since stroke” (calculated in months) and the sum differences between stroke survivors and family members. As with the paired t-test described above, the assumption of normality for the Pearson correlations is tested using the Shapiro-Wilk test, and the assumption of homogeneity of variance was tested according to the guideline suggested by Sani and Todman (2006) described above. Unless stated in the text, these assumptions were met and Pearson correlation coefficients are reported. In other cases, Spearman’s Rank Order Correlations are reported.

Intraclass correlations were used to determine the strength of the agreement, modelled on their use in a wide analysis of patient-proxy responses in QoL measures by Sneeuw et

al. (2002). A one way random model was used (as in similar studies, such as Hays et al., 1995). This test also requires that certain assumptions are met, including that the factor tested must be random and in a normal distribution (McGraw & Wong, 1996). The randomness was built into the study as no fixed variable was used. The tests of normality were conducted as described above. As no non-parametric alternative exists for intra-class correlations, variables were excluded from the analysis if they did not fit the normality assumption, and this was reported in the text.

As the analyses conducted were chosen to directly test the two hypotheses, no post-hoc tests for multiple comparisons were used. While such tests do reduce the possibility of a type 1 error (a false positive result), they increase the possibility of a type 2 error (a false negative). When all comparisons are directly testing the hypotheses, the aim is to detect differences at the specified significance level rather than a more conservative level that takes account of the number of comparisons. In this instance, the risk of rejecting found differences that are otherwise significant is seen as outweighing the risk of obtaining false positives.

### ***3.2 Sample Characteristics***

One hundred and twenty information packs were provided for distribution to individuals who had experienced a stroke within the last five years and were able to provide informed consent. Each potential participant also had to nominate a family member who would also agree to take part. Twenty individuals and their family members returned the consent forms, giving a response rate of 16.6%. The low response rate may be due to

potential participants being excluded on the basis of inclusion or exclusion criteria, as well as individuals declining to participate.

### ***3.3 Demographic characteristics***

#### ***3.3.1 Stroke survivors***

Of the twenty participants who had survived a stroke, there were fourteen males (70%) and six females (30%). The stroke survivor participants were aged between 47 and 86, with a mean age of 64.7 years (SD, 10.9). Eighteen of the stroke survivors were screened for possible cognitive impairment using the 6-CIT, and their scores ranged from 0 to 6, with a mean score of 3.44 (SD, 2.26). Higher scores indicate more errors made, and scores of 8 or over are suggestive of probable cognitive impairment (Brooke & Bullock, 1999). The two patients who did not complete the 6-CIT had marked difficulty in producing speech, and the test was abandoned in both cases as the physical difficulty of listing numbers and months appeared likely to account for most of their errors. In both these cases, it was established that they had been assessed as having intact comprehension and had been legally recognised as possessing capacity to consent. They were therefore accepted for inclusion into the study.

Stroke survivors indicated their subjective level of disability on an ordinal scale from zero to ten. The mean rating was 3.90 (SD, 2.32) and the responses ranged from 0 to 7. The median rating was 5, and the mode was 6. Two survivors indicated that they had no disability.

All participants completed the HADS scale to indicate levels of anxiety and depression. The mean score for depression in stroke patients was 5.45 (SD, 4.37) and responses ranged from 0 to 16. The mean score of anxiety was 7.15 (SD, 5.34) and responses ranged from 1 to 19. 30% of patients were classed as clinical (with a clinical cut-off of 8 or above) on the depression subscale, while 45% were classed as clinical on the anxiety subscale.

The time elapsed since the stroke onset was calculated from the date provided by the stroke survivor until the date of testing. Some participants were able to provide exact days, but most were only certain about the month. The data are therefore recoded as months since stroke onset. The time since stroke ranged from 3 months to 57 months, with a mean of 20.7 months (SD, 17.19) and a median of 18 months. An examination of the histogram suggested that the distribution was not normal, and this was confirmed by the Shapiro-Wilk test.

### 3.3.2 Family members

Of the twenty family members nominated by the stroke survivor participants, there were seven males (35%) and thirteen females (65%). The family member participants were aged between 38 and 82, with a mean age of 58.7 years (SD, 13.5). Seventeen (85%) of the family members were the husband, wife or partner of the stroke survivor, two (10%) were brothers or sisters and one (5%) was the child of the stroke survivor.

Family members also completed the HADS scale. The mean depression score for this group was 4.3 (SD, 3.33) with scores ranging from 0 to 11. The mean anxiety score was 7.45 (SD, 4.74) with scores ranging from 0 to 18.

Further information for both stroke survivor and family member groups can be found in table 3.1.

Table 3.1. Demographic characteristics of participants by stroke survivor and family member group.

<b>Characteristic</b>	<b>Stroke survivors</b>		<b>Family members</b>	
	<b>Mean</b>	<b>SD</b>	<b>Mean</b>	<b>SD</b>
Age	64.7 years	10.9	58.7 years	13.5 *
Time since stroke	20.7	17.18	--	--
Rating of survivor's disability	3.90	2.32	3.85	2.18
HADS Depression	5.45	4.37	4.3	3.33
HADS Anxiety	7.15	5.34	7.45	4.74
	<i>N</i>	%	<i>N</i>	%
<b>Gender</b>				
Male	14	70	7	35 *
Female	6	30	13	65
<b>Marital Status</b>				
Married/partnered	17	80	19	95
Single/divorced	2	15	1	5
Widowed	1	5	0	0
<b>Education level</b>				
Primary/high school	11	55	4	20 *
Higher/further education	9	45	16	80
<b>Living arrangements</b>				
Living with partner/family	16	80	19	95
Living alone	3	15	1	5
Care home/hospital	1	5	0	0
<b>Relationship to family member</b>				
Spouse	17	80		
Sibling	2	15		
Adult child	1	5		
<b>Quality of relationship</b>				
Very good	14	70	12	60
Good	6	30	8	40
<b>HADS score <math>\geq</math> 8 (clinical cut-off)</b>				
Depression	6	30	4	20
Anxiety	9	45	9	45

\*p<0.05, \*\*p<0.01



### 3.3.3 Comparison of group demographic characteristics

As highlighted in table 3.1, the stroke survivors group was significantly older than the family members ( $t(19) = 2.699$ ,  $p < .05$ ). Chi square analyses using Fisher's exact test revealed that the stroke survivors group held significantly more males ( $\chi^2(1) = 4.912$ ,  $p < .05$ ). There was also a significant difference in levels of educational attainment ( $\chi^2(1) = 5.227$ ,  $p < .05$ ), with the frequencies in table 3.1 suggesting that there were higher levels of attainment in the family member group. No significant associations were found between the groups and the quality of their relationships ( $\chi^2(1) = 0.440$ ,  $p = .50$ ), with all participants indicating their relationship was either good or very good, and no significant associations were found between the groups and their living arrangements ( $\chi^2(2) = 2.257$ ,  $p = .32$ ).

Both stroke survivors and family members indicated the level of the survivor's disability. As the data was ordinal, Wilcoxon's Matched-Pairs Test was used to compare the ratings of the two groups and revealed no significant differences ( $Z = 0.146$ ,  $N = 20$ ,  $p = .88$ ).

The depression and anxiety of the stroke survivors was compared with that of the family members. No significant differences were found in depression ( $t(19) = 1.04$ ,  $p = .311$ ) or anxiety ( $t(19) = 2.13$ ,  $p = .034$ ).

### **3.4 Main Hypotheses**

#### **3.4.1 Tests of Hypothesis one**

*It is hypothesised that the discrepancy between patient and family member's perceptions of the patient's Quality of Life will be significantly higher at longer lengths of time since stroke onset.*

Quality of Life was measured by the WHOQOL-BREF (The WHOQOL Group, 1998a), an abbreviated version of the WHOQOL-100 (The WHOQOL Group, 1998b). All participants were asked 26 questions about the stroke survivor's quality of life, and they responded along a five-point scale. The responses were collated and split into the four domains of the WHOQOL-BREF, classified as Physical, Psychological, Social and Environment, as well as the two single-item scores of overall quality of life and overall satisfaction with health. Table 3.2 provides the means and standard deviations of each scale for the two groups of participants, plus the two single item scales. As no comparisons between the different domains were intended, the scores provided for the individual scores were the raw scores and were not subjected to any transformation.

Table 3.2 Means, standard deviations and Intraclass Correlation Coefficients of Quality of Life domain scores in stroke survivor and family member groups.

WHOQOL-BREF	No. of items	Stroke survivors (N=20)		Family Members (N=20)		Intraclass Correlation Coefficients
QoL Domain		Mean	SD	Mean	SD	
Physical	7	22.75	5.91	22.10	4.56	.611
Psychological	6	21.55	3.90	21.20	2.59	.619
Social	3	11.95	3.90	11.00	1.52	-.035
Environment	8	33.15	3.68	31.80	5.73	.784
Overall QoL	1	3.45	1.23	3.55	0.95	
Overall satisfaction with health	1	2.85	1.14	2.75	1.07	

The first hypothesis sought to investigate the relationships between the two scores and time since stroke onset. For this analysis, a new variable (*discrepancy magnitude*) was used to represent the magnitude of the discrepancy within each domain. This was created by subtracting the stroke patients' scores for each item from the equivalent family member scores and then removing any negative signs. This created a discrepancy score for each dyad and each item, where a score of zero indicated no difference between the scores, and a score of four indicated the maximum possible difference. These discrepancy scores were summed for the items within each domain of quality of life.

Before beginning the analysis the data was inspected using scatterplots. The magnitude discrepancy was plotted against the time since stroke for the Physical domain (figure 4), Psychological domain (figure 5), Social domain (figure 6) and Environment domain (figure 7). Figure 4 seems to suggest that discrepancies in the Physical domain may be widely spread in the early stages post-stroke and become less variable in later months, although no linear relationship is apparent. Figure 5 suggests no clear linear relationship in the Psychological domain between discrepancy magnitudes over time. Figure 6 appears to show a linear relationship in the Social domain, with increasing discrepancy magnitudes as time increases. Figure 7 again seems to show greater variability in the Environment domain amongst dyads in the earlier stages, although again there is no apparent linear relationship.

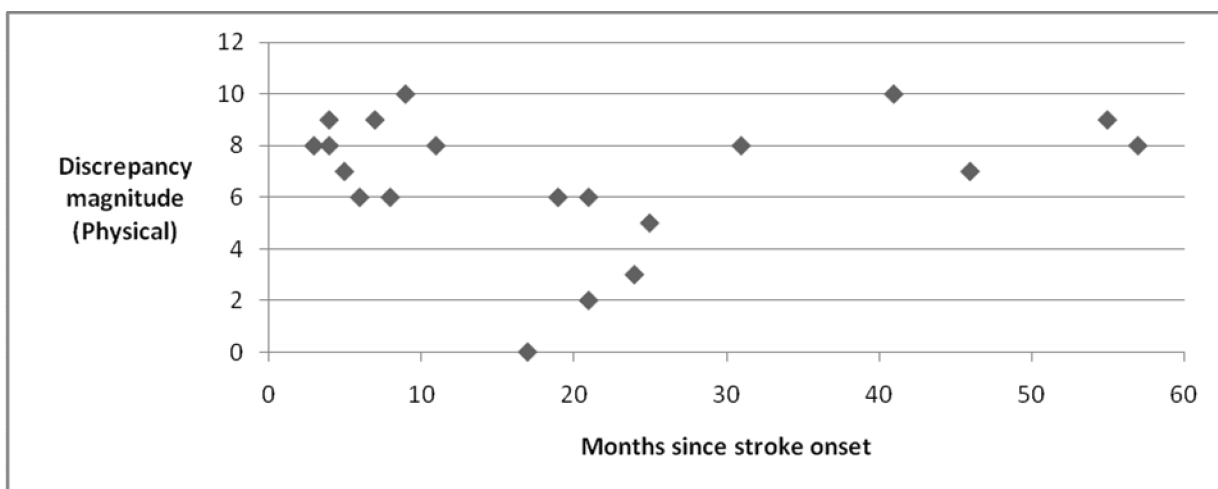


Figure 4- Scatterplot of Physical domain discrepancy magnitude by time since onset

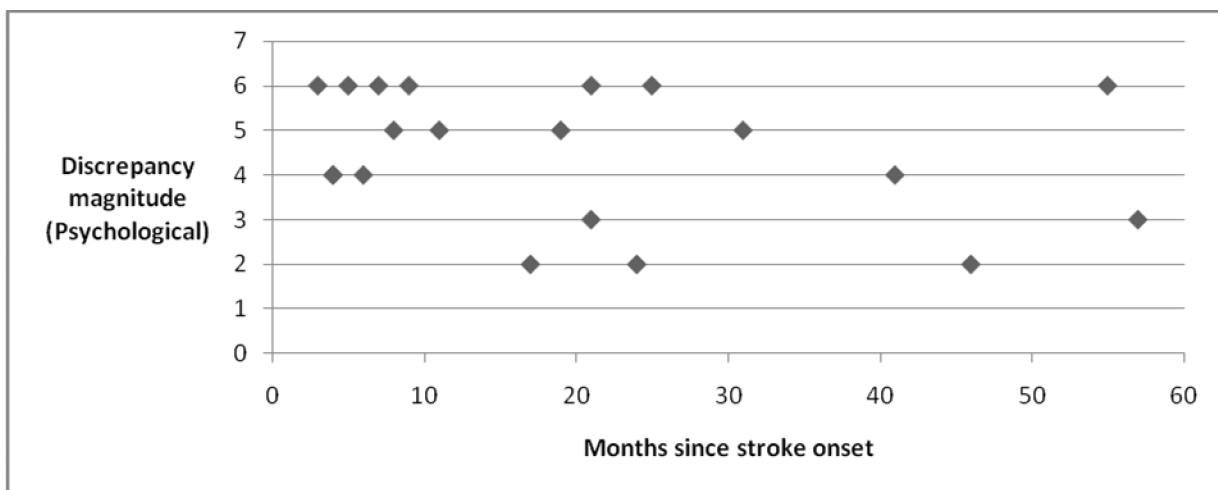


Figure 5- Scatterplot of Psychological domain discrepancy magnitude by time since onset

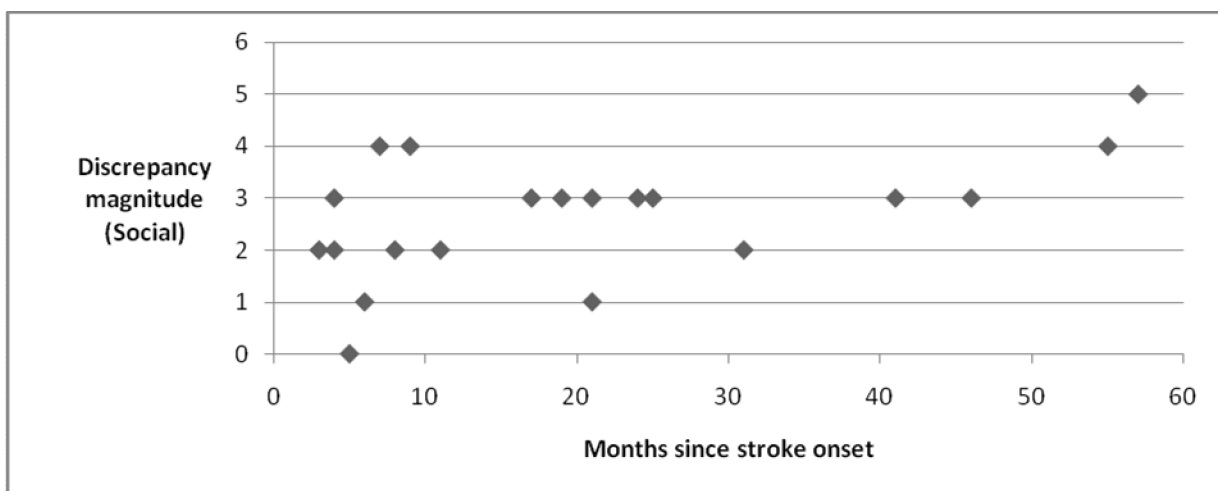


Figure 6- Scatterplot of Social domain discrepancy magnitude by time since onset

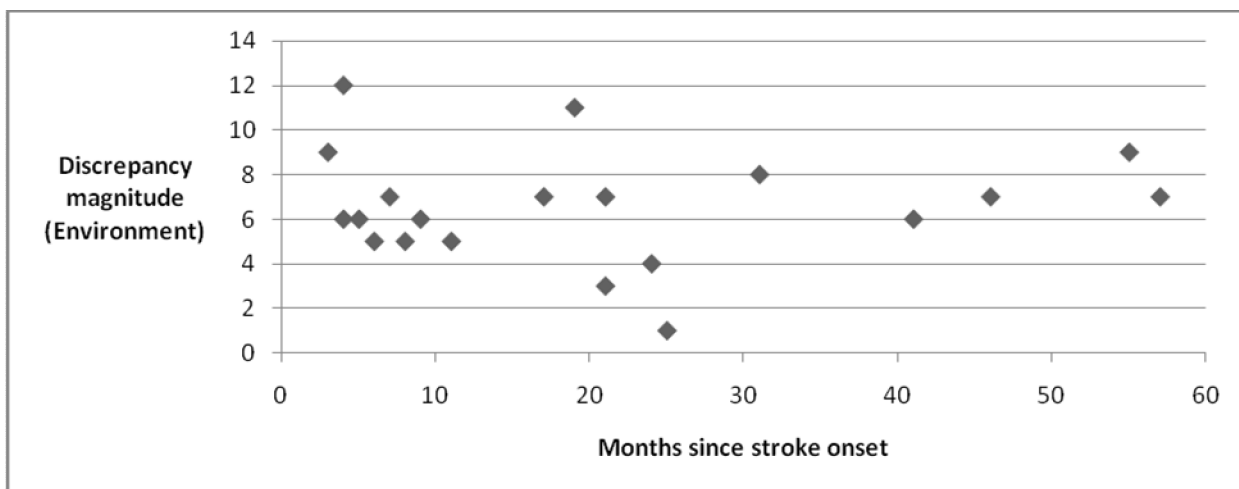


Figure 7- Scatterplot of Environment domain discrepancy magnitude by time since onset

The “Time since stroke” variable was tested for non-normality and the Shapiro-Wilk statistic was found to be significant, indicating that the variable deviated from the normal distribution. All correlations were therefore conducted using non-parametric Spearman correlations. Four correlations were performed in total between the domain

discrepancy magnitudes and the time since stroke onset. Table 3.3 presents the correlation coefficients and significance levels for each analysis.

Table 3.3. Spearman correlations for Time since stroke onset and WHOQOL-BREF domain discrepancy magnitude.

	Correlation with Time since stroke onset	Significance level
WHOQOL-BREF domain		
Physical	- 0.065	.392
Psychological	- 0.255	.139
Social	+ 0.471	.018*
Environment	- 0.032	.447

\* $p < .05$

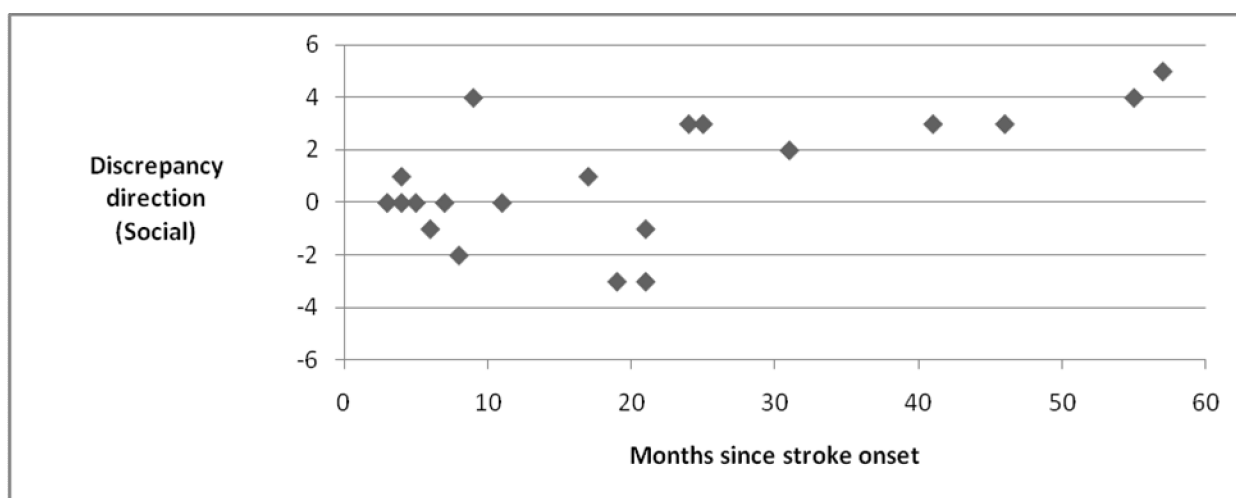
As shown in table 3.3, there was no significant association between time since stroke onset and the discrepancy magnitude of the Physical domain ( $r_s = -0.065$ ,  $n = 20$ ,  $p = .392$ ), Psychological domain ( $r_s = -0.255$ ,  $n = 20$ ,  $p = .139$ ) or Environment domain ( $r_s = -0.032$ ,  $n = 20$ ,  $p = .447$ ). However, there was a significant association between time since stroke onset and the discrepancy magnitude of the Social domain ( $r_s = 0.471$ ,  $n = 20$ ,  $p < .05$ ). From this result and the examination of the scatterplot, this indicates that increased time since stroke onset is associated with greater magnitude of discrepancies

between stroke survivor scores and family member scores of survivor's social domain of quality of life.

In order to further investigate the relationship between stroke survivor and family member scores in the Social domain, it was necessary to examine whether the increasing discrepancy was in a particular direction. A new variable were therefore created to represent the difference between stroke survivor and family member scores for each item. This variable was created by subtracting the family members' domain scores from the stroke survivors' domain scores. Signs were not removed and scores therefore represented the difference in direction, so that positive scores would indicate that stroke survivors were indicating greater satisfaction in the domain than their family members were indicating. Negative scores would indicate that stroke survivors had a lower satisfaction than their family members. For example, if a stroke survivor scores 22 on a domain while his family member scores 18, his score on the new variable would be +4, indicating that he is more satisfied with this area of his life than his family member presumes. The score is indicated by the term *discrepancy direction*.

A scatterplot of discrepancy direction against time since stroke onset is presented in Figure 8. This seems to indicate a possible linear relationship, with discrepancies shifting towards positive scores as time since stroke increases. A Spearman correlation was performed and there was a significant association between discrepancy direction and time since stroke onset ( $r_s = 0.539$ ,  $n = 20$ ,  $p < .01$ ). This suggests that with greater time since stroke, stroke survivors tend to report greater satisfaction within the Social domain of the WHOQOL-BREF than their family members.





*Figure 8- Scatterplot of Social domain discrepancy direction by time since onset*

Finally, the possibility that the higher discrepancy magnitude in the Social domain might contribute to depression in the participants was tested using two spearman correlations. The Boneferroni correction was again applied to the one-tailed significance level, and the required p-value for a 5% significance level was therefore .025. There was no significant association between Social domain discrepancy magnitude and stroke survivor HADS depression score ( $r_s = 0.353$ ,  $n = 20$ ,  $p = .127$ ) or family member HADS depression score ( $r_s = -0.096$ ,  $n = 20$ ,  $p = .686$ ).

### 3.4.2 Interim summary: Hypothesis one

A significant association was found between time since stroke onset and the magnitude of discrepancy in the Social domain of the WHOQOL-BREF. However, no significant associations with time since stroke onset were found in the Physical, Psychological and Environment domains.

Further analysis found a significant relationship between discrepancy direction and time since stroke onset in the Social domain. This seemed to indicate that the widening of the discrepancy between stroke survivors and family members was linked to an increasing bias towards stroke survivors' satisfaction with their quality of life in this domain. No relationship was found between the discrepancy and depression scores for either stroke survivors or family members.

#### 3.4.3 Tests of Hypothesis two

*It is hypothesised that patients and family members will have significantly different scores on the measure of patients' Quality of Life.*

#### 3.4.4 Comparisons of stroke survivors and family members Quality of Life scores

The assumption of normality was investigated for the four domains, with none showing a significant deviation from normality.

There was no significant difference between groups on the Physical domain ( $t(19) = 0.616$ ,  $p=.56$ ), Psychological domain ( $t(19) = 0.444$ ,  $p=.662$ ), Social domain ( $t(19) = 1.808$ ,  $p=.087$ ) or Environment domain ( $t(19) = 1.528$ ,  $p=.143$ ).

#### 3.4.5 Agreement between dyads on quality of life scores

Intraclass correlation coefficients (ICCs) were used to quantify agreement between dyads on quality of life scores. ICCs are based on ANOVA methodology, and are distinct from tests such as Pearson's correlation coefficients because they are sensitive to bias. In a sample where one measurement was always four points higher than the second measurement, a Pearson's (or Spearman's) correlation would indicate that they

were perfectly correlated (McGraw & Wong, 1996). In the instance of the stroke survivors and family members being investigated here, it is important to be aware of the degree of absolute agreement within the dyads, and it would be important to know the degree to which the scores differed whether it were due to bias or random variation.

There are a range of options available when using ICCs. Selecting the correct method involves considering the nature of the variables tested and whether one-way or two-way models are appropriate. One-way models fit designs where the measurements for each subject are made for that person only, so there is no way of telling whether some raters consistently rate higher or lower. Two-way models fit designs where different subjects may be rated by the same person, so the effect of the raters becomes a possible source of variance. The design of the current study fits the one-way model, as each dyad is independent of every other dyad. McGraw and Wong (1996) define this model as measuring “The degree of absolute agreement among measurements made on randomly selected objects. It estimates the correlation of any two measurements”. As there is only one version of the one-way model, further considerations that only apply to the two-way model need not be considered here.

The ICCs for the four key domains are summarised in Table 3.2. The scale used by Sneeuw et al. (1997) to classify ICCs (originally taken from Landis & Koch, 1977) describes ICCs as follows:  $\leq 0.40$ , poor to fair agreement; 0.41 through 0.60, moderate agreement; 0.61 through 0.80, good agreement; and 0.81 through 1.00, excellent agreement. The Physical, Psychological and Environment domains are all within the good agreement range, with Physical and Psychological domains just above the cut-off

for moderate agreement and Environment domain just below the cut-off for excellent agreement. However, the Social domain shows negative agreement, which indicates that agreement is poor in this domain.

#### 3.4.6 Interim summary: Hypothesis two

No significant differences were found between the stroke survivor and the family member groups on their scores for different quality of life domains. The study therefore failed to reject the null hypothesis that there are no differences in between these groups in terms of ratings of stroke survivors' quality of life.

The Intraclass Correlation Coefficients obtained suggest that the Physical, Psychological and Environment domains of the WHOQOL-BREF show good agreement between stroke survivors and family members. The Social domain seems to indicate a very poor agreement within the dyads. However, as other factors may contribute to such a result, this conclusion should only be accepted with caution.

### **3.5 Summary of findings**

In sum, one domain of the WHOQOL-BREF showed greater discrepancies as time since stroke elapsed. However, no evidence of overall difference was found between stroke survivors and family members in measurement of survivors' quality of life. More specifically, the data revealed the following:

- There were no differences between stroke survivors and family members in levels of depression or anxiety.

- There was a relationship between time since stroke onset and the magnitude of the discrepancy between dyads' scores on the Social domain of quality of life. Greater discrepancies are associated with greater time elapsed since the stroke in this domain. There was no equivalent relationship in the other domains.
- As time since stroke increases, the stroke survivors increasingly rate the social aspects of their own quality of life higher than their family members' proxy ratings.
- Higher levels of depression are not associated with greater discrepancy in the social domain.
- There were no overall differences between stroke survivors' and family members' assessments of the stroke survivors' quality of life in the four domains of the WHOQOL-BREF.
- There was good agreement between stroke survivors and family members on three domains of the WHOQOL-BREF. There was very little agreement between groups in the Social domain.

## **Chapter 4. Discussion**

### ***4.1 Interpretation of results***

#### 4.1.1 Changing Quality of Life discrepancies over time.

Unlike most past studies that have looked at the discrepancy between responses given to QoL questions by stroke patients and family member proxies, the current study sought to investigate one of the factors that might affect the accuracy of the proxies. By focussing on the time since stroke, the study aimed to understand something more about the way adjustment and adaptation to stroke is expressed as well as gaining information of the reliability of family members as proxies. The analysis revealed different effects for different domains of QoL. No change in the size of discrepancies was found in Physical, Psychological or Environment domains as time since the stroke increased. However, the discrepancy between stroke survivors and family members in the Social domain was found to increase with passing time. Further analysis revealed that the stroke survivors were responding in an increasingly positive way relative to their family members in this domain. The degree of discrepancy was not found to be related to stroke survivor or family member level of depression.

The participants in this study had suffered a stroke between 3 and 57 months before being tested. From the charts produced, it appeared that the trend of increasing discrepancy was not apparent in the first year, with the dyads at this stage showing a full range of discrepancies. This may suggest that different processes are taking place in the more acute stage of recovery than in the chronic stage. Furthermore, it suggests that

when improvements in function appear to plateau at around 6 months (as described in Verheyden et al., 2008), the family's adaptation to the stroke seems to enter a new stage rather than concluding. From the results obtained, it appears that this stage is reflected in increasing differences of perception between stroke survivor and the family member in judgements of the Social domain of QoL. However, it does not appear to be associated with increasing discrepancy in other domains, with the Psychological domain perhaps being an especially surprising example. Further investigations would be needed to determine if different changes occur in the Psychological domain that could not be measured by the correlational design. For example, discrepancies may be higher in these areas than if no stroke had occurred, but remain constant.

The phases of adjustment of the first year described in Kirkevold's (2002) qualitative study include those of "continued rehabilitation" as the plateau is approached, and the 'semi-stable phase' when improvements in function are minimal. In similar terms, Rolland (1987) describes the chronic stage as following on from the initial adjustment period. The contents of these later stages were hypothesised to include a struggle in all family members struggling to maintain autonomy despite being pulled toward dependency. Perhaps the findings of the current study reflect this struggle, with the negotiation of dependency and autonomy between family members resulting in a discrepancy of views. If this is the case, it appears that the negotiation has favoured the stroke survivors, who are relatively satisfied with their personal relationships, sex life and friends. In comparison, the view of the family member may be seen as "they shouldn't be satisfied with this situation". In any event, the current study has helped to

broaden our understanding of the continued development of the semi-stable or chronic stage, supporting the view that the impact of the stroke is not limited to the period of physical recovery.

The nature of the questions asked of the family members may have been testing the limits of their ability to empathise with the stroke survivor, and the particular causes and effects of these limits were not directly investigated. An interesting study by Labay and Walco (2004) investigated empathy in the siblings of children suffering from cancer. One of their key findings was that healthy siblings were less successful in areas of social competence than control groups, although those with greater empathy experienced fewer difficulties in this regard. Counter-intuitively, they also found that warmer relationships between siblings predicted poorer adjustment. This suggests that increased understanding of the other's feelings coupled with a degree of emotional distance give the siblings the best outcomes. Although this group clearly differs substantially from stroke patients and their families, a similar result within the stroke population might be possible, potentially leading to therapeutic approaches targeted for this group.

A disadvantage of the current study is that the process of responding to questionnaire items is invisible, and all we can report is the final outcome. Integrating the current quantitative study with those that have used qualitative methodologies may allow some insight into the reasons for these outcomes. The focus-group study reported by Lynch et al.(2008) is particularly useful, as it suggests that stroke survivors and family members may struggle with different difficulties initiated by the stroke. Patients and caregivers also had contradictory perspectives on the stroke's trajectory, with patients



concentrating on challenges met and conquered while caregivers felt this represented a denial of the true impact of the stroke. The poor agreement between patients and caregivers in the social domain may be partly explained by the difference in what matters to the two parties. Stroke survivors' evaluation of what matters to their lives may change over time, as suggested by research on 'Response shift'. Individualised QoL measures such as the SEIQoL-DW (Hickey et al., 1996) are designed to allow participants full expression of the importance and satisfaction of the different elements of their life, and further research using such measures with stroke patients and their families might reveal where the underlying differences lie.

A question also not answered by this study, or possibly any study to date, is the degree to which families return to the patterns of interaction that characterised their pre-stroke life. Although most theories of adjustment include the sudden change from old life to the new, there are great practical difficulties to be overcome in testing people before and after a stroke. Instead, we may have to rely on the memories of stroke survivors and their families of their past QoL, and there is some evidence that these are not always reliable (Allison, Locker, & Feine, 1997; Bernhard et al., 2004). The effect of response shifts is essentially to move the goalposts so that different aspects become important and desirable, and estimates of past QoL are seen using the current standards rather than those in the past. An alternative perspective on the increasing divergence of views of the patient's social QoL may be that the patients are gradually returning to the wide divergence in views that existed before the stroke. Cummins (2000) suggests that when objective QoL is very low, as when health is very poor, it is closely tied to subjective

measures of QoL. Perhaps in the early stages following a stroke it is much easier to estimate another's QoL, while improvements in function lead to subjective and objective QoL becoming detached, and therefore much more difficult to discern.

Brennan's (2001) description of the Social Cognitive Transition (SCT) model suggests that the process of adjustment to illness is shaped by the mismatch of our new experiences with our assumptions about ourselves and the world. It might be assumed that the SCT model would predict a gradual convergence of assumptions, as the illness experiences gradually become incorporated into the schema of both patient and loved ones. However, the current research may be suggesting that the stroke survivor and family member are subject to different experiences relative to their assumptions, leading to greater discrepancies over time. The fear and anxiety that accompanies the patient's admission to hospital may be quite different for patient and family member, and may challenge the assumptions of each in different ways. As recovery progresses, the patient may initially respond to their loss of function by denying such a loss, while the family member may have the experience of witnessing this denial in the face of clear deficit. There may be no 'correct' assumption at the end of this process, only a continuing process as both strive to create the most inclusive picture of their experiences.

The finding that discrepancy was not related to levels of depression may appear to limit the usefulness of considering differing views of patient and family member. As the correlation with stroke survivor appeared to approach significance, it is possible that the effect was simply too small for this study to detect. However, the aim of this study was to investigate natural adjustment to stroke over time, and there is no clear evidence to

date that depression is more or less likely as time increases. There is evidence that depression represents the gap between present QoL and the hoped-for future QoL (Moore, Hofer, McGee, & Ring, 2005) and this may suggest that the discrepancy between patient and family member views of patient QoL is not analogous to the gap between present and future. Discrepancy within a family may be uncomfortable, but it may not be a major contributor to depression.

#### 4.1.2 Different perceptions of Quality of Life between patient and family members

This study also aimed to determine if there were overall differences between patients and their family members' view of the patient's quality of life. The results indicated that there were no overall differences within the participant dyads on the four domains of the WHOQoL-BREF. The level of agreement between the family members and stroke survivors for each quality of life domain was also quantified using intraclass correlation coefficients (ICCs), and this analysis produced a mixed result. The Physical, Psychological and Environment domains all showed good agreement. However, the result in the Social domain was suggestive of poor agreement.

The lack of overall difference found within the dyads does not necessarily demonstrate that no difference exists, but it does suggest that the size of such an effect is unlikely to be large. This is consistent with those studies that have investigated patient-proxy differences in stroke patients (Sneeuw et al., 1997) and other patient populations (Sneeuw et al., 2002), where differences in QoL scores have tended to be of a small to medium effect size. While there is no universally accepted point at which the difference between groups is seen as small enough to be inconsequential, small and medium effect

sizes suggest that family members can provide responses on behalf of the patient that are broadly similar to those the patient would give, at least when aggregated.

Authors with similar results have come to divergent conclusions when deciding whether proxies may provide an acceptable alternative to the patient. While one study concludes that the correlation between proxies and patients is not high enough for use as a substitute (Rothman, Hedrick, Bulcroft, Hickam, & Rubenstein, 1991), Sneeuw et al. (2002) argue convincingly that the clear majority of responses either agree or are only one response category away, with a handful of major differences being responsible for moderate ICCs. Overall, they conclude that the judgements made by proxies are reasonably accurate. For the purposes of including patients in important studies who would otherwise be excluded, this seems a fair conclusion. However, it is also clear that in individual questions and in some domains, the perspective of the patient may be quite different to those who know the patient best, and the research does not seem to support the use of family members as proxies as a routine.

Why should social aspects of QoL be more susceptible to poor agreement than other aspects? One possibility is that family members have relatively little information on which to base their responses. The three questions that constitute the WHOQOL-BREF Social domain ask about satisfaction with personal relationships, sex life and friends, and it may be that the family member becomes a subject of these questions in a way that is not found in the other domains. As the majority of the family member group were the spouses of the stroke survivors, a patient's personal relationships are very likely to include the family member also completing the questionnaire, a situation even clearer

when the patient's sex life is questioned. Communication between the partners on these subjects may be comparatively rare, and may be avoided by either to avoid difficult or awkward discussions. This hypothesis was not directly tested in the current study and would require substantiation from further research.

Alternatively, spouses may tend to confuse the views and feelings of their family member with their own feelings. There is evidence that marital relationships suffer as a result of the role changes and slow recovery after a stroke (Green & King, 2007) and that some of these strains are felt as more important by one of the couple than the other. One possibility is that while family members are able to identify the views of the patient, these are not necessarily in accordance with their own views. Lynch et al. (2008) suggest that differences in perspectives may cumulatively increase the strain on the relationship, and this strain may be reflected in the family member's negative perception of these relationships. Social relationships may become the battleground in which all the other difficulties are expressed. Family members could be asked to complete QoL questions from the patient's perspective and from their own perspective, allowing insight into what the proxies think it is versus what they think it should be. The results of such a study might help to support or reject this hypothesis.

The results obtained allow comparisons to be made with other studies of stroke patients and their proxies. Using the Sickness Impact Profile (SIP) as the chosen measure of QoL, Sneeuw et al. (1997) found significant differences between stroke survivors and their proxies in the physical domain and psychosocial domain, as well as in seven of the eleven subscales measures. Their study included 229 pairs of stroke survivors and

family members and so had far greater power to detect the low to moderate differences found than in the current study. Although the current study did not find a significant result, the difference in mean scores was in the same direction in both studies, with both indicating that stroke survivors had reported higher QoL in each domain than their proxies.

The ICCs for Physical, Psychological and Environment domains may be compared with those found in the stroke survivors of Sneeuw et al. (1997). They revealed ICCs showing excellent agreement for the Physical domain of the SIP, and good agreement for the Psychosocial domain. Although the Physical domain of the SIP shows an ICC at a higher level than the equivalent domain in the WHOQOL-BREF, both scales seem to show broadly acceptable ICCs for these domains. Of course, it is unknown whether the Psychosocial domain of the SIP is equivalent to either the WHOQOL-BREF domains of Psychological or Social, or perhaps a combination of the two. There is a social subscale in the SIP, and the ICC for this was on the low end of the “fair agreement” range, lower than any of the other subscales or domains. In this respect then, the two studies both seem to indicate that questions of social QoL show poorer agreement between stroke patients and proxies than other types of QoL questions.

This is the first study to investigate the substitution of proxies for stroke patients using the WHOQOL-BREF and the results seem to indicate that it has comparable responses to the SIP, based on the study reported by Sneeuw et al.(1997). Similar studies using the EuroQoL measure (Dorman, Waddell, Slattery, Dennis, & Sandercock, 1997a) and the SF-36 (Segal & Schall, 1994) reveal overall agreement of a moderate level. The wider

review of such studies conducted by Sneeuw et al. (2002), including many other patient populations, concluded that very few studies had found overall ICCs lower than the moderate level. However, a table from their paper providing the ICCs for each comparable domain showed that social domains were at a poor level of agreement in six of the twenty results included. In contrast, only one of twenty-two physical domain correlations was at this level. The current study using the WHOQOL-BREF with stroke survivors and their family members seems to support this trend.

#### 4.1.3 Demographic variables

All participants indicated that their relationship with the other respondent was either good or very good. It is possible that social norms could prevent participants from reporting an unfavourable relationship with their family member, although the fact that the family members were nominated by the stroke survivors as someone who knows them well could suggest that the relationships are close.

More males than females were the stroke survivors in the study. As the majority invited their partners to act as their nominated family members, this led to more females in the family members group. This may reflect the greater prevalence of first-time strokes among males (G. R. Williams et al., 1999). The literature review reported by Green and King (2007) explicitly included only those studies that investigated male stroke survivors and female caregivers, on the grounds that these represented the most common outcome from stroke. While this is certainly true, there do not seem to be compelling reasons to believe that the pattern of adjustment in females is different to that in males,

and therefore it was felt including patients from whichever gender was appropriate for this study.

The level of education obtained by stroke survivors was found to be lower than their family members. This may be partly explained by the younger age of the family members, and the increasing opportunity for higher and further education in recent years. It may be worth noting that many of the participants who had indicated finishing their education in high school or earlier had found very well-paid employment, perhaps indicating that their years of education was an unreliable guide to their intellectual abilities.

A range of subjective levels of disability were reported by stroke survivors. As participants were also recruited at different timepoints since the stroke, the levels of disability reported may have reflected the situation while improvements were still apparent in some and improvements had slowed in others. Participants were recruited from among those receiving assistance from the Stroke Unit or CHSS, and so those with extremely mild strokes may have been under-represented in the sample. Mild-stroke survivors have been studied by other researchers (Carlsson, Möller, & Blomstrand, 2003, 2004) and may have particular difficulties to address. However, the wide range of patients in the current sample may allow the results to be generalised to most patients.

Depression and anxiety levels were not significantly different between stroke survivors and family members. This is consistent with some findings from previous studies, which have suggested that symptoms of anxiety and depression in stroke survivors



influence the psychosocial burden of their family members (Fure, Wyller, Engedal, & Thommessen, 2006).

## **4.2 Strengths and limitations**

### 4.2.1 Statistical power analysis

The power analysis performed while the study was being designed suggested that a sample size of twenty participants per group was necessary to reveal a large effect size using related samples comparisons. Similarly, twenty dyads were needed to detect a correlation of .6 with sufficient power. A large effect size was sought partly due to a realistic estimate of the possible scope of the study, and partly because smaller effects may be of more limited interest or clinical use. Twenty dyads were successfully recruited, thereby attaining the required power. The fact that significant results were obtained suggests that this strategy was successful. However, with greater samples comes greater confidence in the results. This study has explored a new possibility in the measurement of adjustment following stroke, and executing further research in this area using larger samples is now supported.

An alternative method of analysis had been devised in case the study was able to recruit far more participants than anticipated. Rather than a correlational design, the study would split groups into two groups at different stages in their stroke recovery. One would be in the acute stage at less than six months, while the other would be in the chronic stage at more than six months. Comparisons between groups could therefore be made. While this design could have supported the hypothesis that different stages following a stroke are associated with different outcomes, there were shortcomings with

this design. It would be likely that there would be greater variability among patients in the chronic group, as this represented a much wider period of time. It would be difficult to demonstrate that the groups were substantially different without excluding patients around the transition between acute and chronic stages, and arguably these patients would be among the most interesting to study. Finally, approximately double the number of participants would be required to compare the two groups with adequate power. In the event, it soon became clear that this number could not be obtained in the time available. The correlational approach was therefore the one followed. Again, the significant results suggest that this design was adequate to obtain satisfactory results based on the hypotheses.

#### 4.2.2 Use of QoL domains

Throughout the study, the domains of the WHOQOL-BREF were used in preference to the total scores. The disadvantages of this decision may be an emphasis on specific but minor problems, rather than considering how the person's QoL is as a whole. The Social domain may show discrepancies, but if the social domain is not important to the patient's overall QoL, the discrepancy may be ultimately irrelevant to the patient. However, the decision was made that this study should seek to follow the design and analysis of the studies it most closely resembles, such as the research study and review carried out by Sneeuw and colleagues (1997; 2002). In these, and in many other papers studying the QoL of patients with chronic illness, preference was given to QoL domains. There are good reasons for this practice. While a total score may have some value in particular settings, major difficulties in isolated areas of life are likely to be masked by

scores where no difficulty would be expected. In the case of the WHOQOL-BREF, the Environment domain includes items that are likely to be shared by people who live in similar areas. In the Highlands, for example, most respondents might be expected to indicate that their physical environment was healthy. Additionally, the development of the scale was based on a definition of QoL that explicitly refers to different areas of life, and the four domain model was supported by confirmatory factor analysis (The WHOQOL Group, 1998b).

The two global measures of QoL were not included in the analyses. This decision was partly based on the desire to keep the number of multiple comparisons to a minimum. Performing multiple comparisons risks increasing the chance of failing to reject the null hypothesis when it is true, known as a Type 1 error. In addition, the psychometric properties of the global measures have not been extensively assessed alongside the domains (Skevington et al., 2004), instead using them as benchmarks to assess the domains use. Single-item measures tend to be less reliable and more prone to cognitive biases (Bowling, 2005), such as the mood of the respondent at the time the test is administered (Atkinson & Caldwell, 1997).

#### 4.2.3 Study design

This study included a correlational design and a related-subjects design. No variables were directly manipulated, and the primary dependent variables were the time since stroke and the QoL score for stroke survivors and family members. The study was therefore observational in nature, describing the different responses of stroke patients and their families rather than clearly demonstrating which factors affect these responses

by holding some variables steady and manipulating others. This limits the type of conclusions that can be drawn about the dyads. We could not say that the discrepancy between stroke survivors and family members increased as more time elapsed, only that greater discrepancies were associated with dyads for whom more time has elapsed. It is possible that those who completed the study at later stages would have given very similar answers at an earlier stage and vice versa.

The only way to completely avoid this pitfall is to run a longitudinal study, where the change in individuals can be directly observed. However, such investigations are difficult to run for a range of reasons, not least of which is the necessary time required to devote to the experiment. In order to look at stroke patients at a range of time points over five years, the study will necessarily take at least five years to execute. The initial pool of participants would need to be of sufficient size to allow for withdrawals from the study, and the contact details of participants would require regular updating. Finally, the results may be contaminated by cohort effects, where observed changes may be due to factors unique to that point in time. For example, if the followed cohort happens to have their stroke at around the same time of a severe influenza outbreak, their recovery may be affected by the relatively limited care available to them in the first six months, and it may be difficult to generalise results to patients in other years. Although longitudinal studies can provide a great deal of useful information, it is notable that the longitudinal studies carried out on stroke patients have tended to focus on a very limited timeframe (King et al., 2002) or collected data at distant timepoints (Dam, 2001). The current study suffers from the pitfalls associated with correlational studies described earlier, but

the method chosen does allow an early examination of the adjustments to stroke within a five-year period. This may support future longitudinal research in this area.

The current study did not include a control group of healthy volunteers. Such an inclusion would have allowed a direct comparison of dyad discrepancy with and without stroke. However, it is not clear what additional conclusions could have been drawn had healthy volunteers been included. The second hypothesis sought to examine if a dyad discrepancy existed or not, and this judgement would not be altered by comparison with a control group. No equivalent of the widening discrepancy at different timepoints could have been meaningfully used with healthy volunteers, since there would be no equivalent to the stroke onset to allow comparisons. The comparison of an alternative medical condition could be possible, such as an amputation or another neurological diagnosis such as multiple sclerosis, and this might allow analysis of the differences in adjustment between different categories of illness according to Rolland's (1987) model. However, analysis of these interesting comparisons would be testing something beyond the aims of the current study.

#### 4.2.4 Recruitment

This study included people who had suffered a minor stroke, with no language or cognitive problems severe enough to prevent provision of consent. As these are the people who are most likely to be offered some form of individual psychological therapy, this does not necessarily reduce the generalisability of the results in practice. However, a large section of the stroke population is certainly excluded from this study, and this may well include those who suffer the greatest psychological distress following their

stroke. While the hope is that the process of adjustment to stroke is similar, this cannot be known without the benefit of further research. One study has specifically investigated the QoL discrepancy between aphasic patients and their family members (Cruice et al., 2005), finding that aphasic patients showed similar discrepancies to those found in non-aphasic stroke patients.

Family members were selected by the patient, and while all relationships were reported to be good or very good, not all relationships may have been equivalent. Relationships between spouses may be of a fundamentally different quality than relationships with siblings or children, and different patterns of QoL discrepancies may be observed. An alternative approach would be to ask patients to nominate their caregivers instead of family members. Care may not have been provided by the participants of the current study, and it might be expected that a group composed of nominated caregivers would be better able to accurately estimate the patient's QoL. However, caregivers might be more likely to be affected by the burden of the patient's poor health, leading to greater pessimism of the patient's QoL. This might be investigated in future studies, although it should be noted that some of the stroke survivors included in this study had recovered to the degree that they might have been unable to nominate a caregiver.

This study sought to include any stroke patient who had sufficient cognitive ability to understand the nature of the study, and sufficient language ability to understand the study and communicate their consent. These criteria were deliberately wide, with the aim of both maximising the generalisability of the study and increasing the potential pool of participants, and was developed in consultation with speech and language

therapists from the stroke unit. A brief test of cognitive function (the 6-CIT) was included for stroke survivors, and all who completed it achieved a score indicative of no cognitive impairment. However, two patients with difficulties in producing speech found the 6-CIT impossible to complete due to their difficulties. This unforeseen problem was due to the two items on the 6-CIT requiring participants to vocalise counting and listing the months of the year. Both participants were able to effectively communicate through pointing, and had each been referred by a speech and language therapist, but attempting to vocalise for an extended duration ran the risk of exhausting and demoralising the participants for limited benefit. With their permission, the patients' nominated family members were able to indicate that the patients had undergone past cognitive testing with no impairment detected, and had been judged able to consent in other areas of their life. Based on this information, and in consultation with a speech and language therapist, it was agreed that the patients could continue with the study. The family members assisted with the demographics questions where pointing was not possible (the participant's age and occupation), but were not present for other questions. No other difficulties were found during the testing.

The 6-CIT had been selected because of its brevity and satisfactory psychometric properties described in an earlier section. However, it was not piloted on aphasic patients when this would likely have revealed the inherent difficulties associated with its use on this population. The CAMCOG (de Koning et al., 1998) has also been validated for use with stroke patients, as has its shortened version (Winkel-Witlox, Post, Visser-Meily, & Lindeman, 2008), although both measures are again unsuitable for patients

with severe aphasia. No instrument measuring cognitive function was used in the study of aphasic QoL undertaken by Cruice et al. (2005), suggesting that the exclusion of patients with cognitive function is not sufficiently useful in this population to counteract the difficulties involved. Other authors suggest a range of techniques for establishing consent, with no one method being without pitfalls (Penn, Frankel, Watermeyer, & Muller, 2009). At present, researchers should continue to think carefully about the costs and benefits of including patients with aphasia in their investigations.

### ***4.3 Clinical implications***

Many possible clinical implications may be evident from the results of this study. Perhaps most clearly, it underlines the importance of obtaining information about patients and families from multiple sources when conducting an assessment. It is probably not helpful to view any one correspondent as being more correct than any other, but awareness that differing views represent particularly rich information about the struggles facing a patient and their family may aid the construction of a useful formulation.

The results obtained from this study suggest that particular attention be given to the social life of the patient. Such an emphasis has been suggested in past studies (Carlsson et al., 2007; Lynch et al., 2008; Robinson, Murata, & Shimoda, 1999), but the current study extends this to considering the discrepancy between patient and family views. Patients and families may have different expectations for the patient's social life, and one may be relatively content while the other continues to hope for more. Hatchett, Friend, Symister and Wadhwa (1997) have reported that patients who feel that their



family's high expectations for their recovery are not being met show poorer quality of life in three months. Some loss of social activity may be acceptable for the patient, while this loss places additional strain on the family resources. In some cases, increasing communication between the parties may lead to agreed goals that are acceptable to all.

A key element of the Social domain of the WHOQOL-BREF was the patient's satisfaction with their sex life. Sexual activity is known to decrease following a stroke in many cases (Korpelainen, Nieminen, & Myllyla, 1999), but the impact of this on the patient may not be obvious to caregivers. There is some evidence that improving communication between couples may increase sexual satisfaction (Hawton, Catalan, & Fagg, 1992) although trials of such therapy applied to stroke patients have not been reported.

The study by Evans et al. (1989) suggests that certain kinds of distress in families may be adaptive for the patient. It might be tempting to view any distress as a symptom to be prevented or alleviated, but it may be important to reflect whether the distress serves a function that is difficult to replace. Although the current study shows an increasing discrepancy between the impressions of stroke survivors and their family members, such discrepancies may not necessarily need to be addressed. Part of the aim of this study was to explore the natural pathway of recovery and adjustment to the sudden and serious demands of a stroke. Such information may help clinicians decide whether a patient in the earlier stages of stroke is 'on the right track' in terms of their recovery, rather than seeking to immediately remove their current distress.

#### **4.4 Future research**

The current study may be seen as a small step towards greater understanding of the adjustment trajectory following stroke. It is possible to imagine many other studies that could continue this endeavour, and many that have been proposed throughout this discussion will not be repeated here. Research using longitudinal methodology could allow the progress of individuals to be charted, while similar methods to the current study might be used to further focus on the changing discrepancies of social QoL over time. In particular, further investigations of the natural trajectory following stroke may allow researchers to identify those patients whose trajectory is likely to lead to increased distress and develop interventions to help move them towards a more adaptive path. Certainly, this appears to be an area of psychological research where the difficulties of defining the problem are beginning to be overcome, and work can now focus on responding to the problem.

#### **4.5 Conclusion**

The aim of this exploratory study was to determine whether the discrepancy in the estimations of stroke survivors' QoL between stroke survivors and their family members is associated with time since stroke, as well as to establish the overall degree of discrepancy. Stroke survivors and their family members were therefore assessed using a measure of QoL, with the time since their stroke also being recorded. Results indicated that a relationship between time since stroke onset and the discrepancy between stroke survivors and their family members was present in the Social domain, although this was not found in the other three domains. There were no overall differences in the assessment of the stroke survivors' QoL in the four domains of the QoL measure. While

good agreement between stroke survivors and family members was found in three domains, results showed there was little agreement in the social domain. The results were interpreted as possibly due to a range of processes, such as family members failing to identify a response shift in the stroke survivors' evaluation of their lives, and this may be part of a natural trajectory of adjustment to a stroke.

There are wider implications stemming from this study and the literature reviewed within it. The finding that family members may struggle to accurately report aspects of the patients' QoL in some circumstances should not only be seen as an accounting problem, where two equivalent equations arrive at contradictory answers. An acceptance that the patient and family member are part of a moving interaction in the time following a stroke, where the responses of one party to the views and behaviours of the other leads to a further series of responses, may help us begin to understand the wider systems of illness and recovery.

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## **APPENDICES**



## **APPENDIX 1**

### **The 6-Item Cognitive Impairment Test (6-CIT)**

### Six-Item Cognitive Impairment Test

	Maximum error	Score	Weight	Weighted Score
1. What <b>year</b> is it now?	1	.....	x 4	=.....
2. What <b>month</b> is it now?	1	.....	x 3	=.....

Memory phrase- *Repeat after me*

*"John / Brown / 42 / West Street / Bedford"*

3. About what <b>time</b> is it (within 1 hour)?	1	.....	x 3	=.....
4. <b>Count backwards</b> from 20 to 1?	2	.....	x 2	=.....
5. Say <b>months of the</b> <b>year in reverse</b> order?	2	.....	x 2	=.....
6. Repeat the <b>memory</b> <b>phrase?</b>	5	.....	x 2	=.....

Score 1 for each incorrect response

Total =

A score of 8 or higher indicates probable cognitive impairment.

## **APPENDIX 2**

### **Demographic Questionnaire (Stroke survivor)**

## **Demographics Questionnaire- About You**

Before you begin we would like to ask you a few questions about yourself.

Please respond by circling or ticking the correct answer or by filling the space provided

1. What is your gender?

- Male
- Female

2. What is your date of birth?

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
Day Month Year

3. What is your marital status?

- Single
- Married
- Partnered (other than married)
- Separated/ Divorced (not currently partnered)
- Widowed

4. Living arrangements:

- Living alone
- Living with partner/spouse
- Living with partner/spouse and family
- Living with family in their home
- Living in residential care
- Other: Please specify

\_\_\_\_\_

5. What is/was your occupation?

\_\_\_\_\_

6. What is the highest level of education you received?

- Primary school
- High school
- Trade or technical certificate
- College diploma or degree
- University degree
- Postgraduate degree

7. What is the nature of your relationship with the family member also completing these questionnaires?

- My Husband/ Wife
  - My Brother/ Sister
  - My Daughter/ Son
  - My Daughter-in-law/ Son-in-law
  - My Mother/ Father
  - Other: Please specify
- 

8. What is your relationship like with this family member?

- Very good
- Good
- Neither good nor poor
- Poor
- Very Poor

9. Have you ever had a stroke? Yes / No

If yes, when did you have this stroke? \_\_\_\_\_ / \_\_\_\_\_  
Month Year

10. How disabled do you currently feel yourself to be?

Not at all  
disabled

Completely  
disabled

0 1 2 3 4 5 6 7 8 9 10

**Thank you for your time.**

## **APPENDIX 3**

### **Demographic Questionnaire (Family member)**

## Demographics Questionnaire- About You

Before you begin we would like to ask you a few questions about yourself.

Please respond by circling or ticking the correct answer or by filling the space provided

1. What is your gender?

- Male
- Female

2. What is your date of birth?

\_\_\_\_\_/\_\_\_\_\_/\_\_\_\_\_  
Day Month Year

3. What is your marital status?

- Single
- Married
- Partnered (other than married)
- Separated/ Divorced (not currently partnered)
- Widowed

4. Living arrangements:

- Living alone
- Living with partner/spouse
- Living with partner/spouse and family
- Living with family in their home
- Living in residential care
- Other: Please specify

\_\_\_\_\_

5. What is/was your occupation?

\_\_\_\_\_

6. What is the highest level of education you received?

- Primary school
- High school
- Trade or technical certificate
- College diploma or degree
- University degree
- Postgraduate degree

7. What is the nature of your relationship with the family member also completing these questionnaires?

- My Husband/ Wife
  - My Brother/ Sister
  - My Daughter/ Son
  - My Daughter-in-law/ Son-in-law
  - My Mother/ Father
  - Other: Please specify
- 

8. What is your relationship like with this family member?

- Very good
- Good
- Neither good nor poor
- Poor
- Very Poor

9. Have you ever had a stroke? Yes / No

If yes, when did you have this stroke? \_\_\_\_\_ / \_\_\_\_\_  
Month Year

10. How disabled do you currently feel your family member to be?

Not at all  
disabled

Completely  
disabled

0 1 2 3 4 5 6 7 8 9 10

**Thank you for your time.**



## **APPENDIX 4**

### **World Health Organisation Quality of Life Short Measure (WHOQOL-BREF)**

## WHOQOL-BREF

The following questions ask how you feel about your quality of life, health, or other areas of your life. I will read out each question to you, along with the response options.

**Please choose the answer that appears most appropriate.** If you are unsure about which response to give to a question, the first response you think of is often the best one. Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last four weeks**.

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents you from doing what you need to do?	5	4	3	2	1
4.	How much do you need any medical treatment to function in your daily life?	5	4	3	2	1
5.	How much do you enjoy life?	1	2	3	4	5
6.	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are you able to concentrate?	1	2	3	4	5
8.	How safe do you feel in your daily life?	1	2	3	4	5
9.	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about how completely you experience or were able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do you have enough energy for everyday life?	1	2	3	4	5
11.	Are you able to accept your bodily appearance?	1	2	3	4	5
12.	Have you enough money to meet your needs?	1	2	3	4	5
13.	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14.	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are you able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are you with your sleep?	1	2	3	4	5
17.	How satisfied are you with your ability to perform your daily living activities?	1	2	3	4	5
18.	How satisfied are you with your capacity for work?	1	2	3	4	5
19.	How satisfied are you with yourself?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
20.	How satisfied are you with your personal relationships?	1	2	3	4	5
21.	How satisfied are you with your sex life?	1	2	3	4	5
22.	How satisfied are you with the support you get from your friends?	1	2	3	4	5
23.	How satisfied are you with the conditions of your living place?	1	2	3	4	5
24.	How satisfied are you with your access to health services?	1	2	3	4	5
25.	How satisfied are you with your transport?	1	2	3	4	5

The following question refers to how often you have felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do you have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

**Do you have any comments about the assessment?**

## **APPENDIX 5**

### **Proxy-version of World Health Organisation Quality of Life Short Measure (WHOQOL-BREF)**

## WHOQOL-BREF -Proxy

The following questions ask how you feel about your family member's quality of life, health, or other areas of their life. I will read out each question to you, along with the response options. Please choose the answer that appears most appropriate. If you are unsure about which response to give to a question, the first response you think of is often the best one.

Please keep in mind their standards, hopes, pleasures and concerns. We ask that you think about their life in the last four weeks.

		Very poor	Poor	Neither poor nor good	Good	Very good
1.	How would you rate your family member's quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2.	How satisfied are they with their health?	1	2	3	4	5

The following questions ask about **how much** your family member has experienced certain things in the last four weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3.	To what extent do you feel that physical pain prevents him/her from doing what they need to do?	5	4	3	2	1
4.	How much does he/she need any medical treatment to function in his/her daily life?	5	4	3	2	1
5.	How much do they enjoy life?	1	2	3	4	5
6.	To what extent do they feel their life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7.	How well are they able to concentrate?	1	2	3	4	5
8.	How safe do they feel in their daily life?	1	2	3	4	5
9.	How healthy is their physical environment?	1	2	3	4	5

The following questions ask about how completely your family member has experienced or was able to do certain things in the last four weeks.

		Not at all	A little	Moderately	Mostly	Completely
10.	Do they have enough energy for everyday life?	1	2	3	4	5
11.	Are they able to accept their bodily appearance?	1	2	3	4	5
12.	Have they enough money to meet their needs?	1	2	3	4	5
13.	How available to them is the information that they need in their day-to-day life?	1	2	3	4	5
14.	To what extent do they have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither poor nor good	Good	Very good
15.	How well are they able to get around?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
16.	How satisfied are they with their sleep?	1	2	3	4	5
17.	How satisfied are they with their ability to perform daily living activities?	1	2	3	4	5
18.	How satisfied are they with their capacity for work?	1	2	3	4	5
19.	How satisfied are they with themselves?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
20.	How satisfied are they with their personal relationships?	1	2	3	4	5
21.	How satisfied are they with their sex life?	1	2	3	4	5
22.	How satisfied are they with the support they get from their friends?	1	2	3	4	5
23.	How satisfied are they with the conditions of their living place?	1	2	3	4	5
24.	How satisfied are they with their access to health services?	1	2	3	4	5
25.	How satisfied are they with their transport?	1	2	3	4	5

The following question refers to how often your family member has felt or experienced certain things in the last four weeks.

		Never	Seldom	Quite often	Very often	Always
26.	How often do they have negative feelings such as blue mood, despair, anxiety, depression?	5	4	3	2	1

**Do you have any comments about the assessment?**



## **APPENDIX 6**

### **Hospital Anxiety and Depression Scale (HADS)**



## **APPENDIX 7a**

**Invitation letter from the Stroke Unit consultant physician**

## **APPENDIX 7b**

**Invitation letter from the Director of Advice and Support  
(Highland Region) of CHSS**

Invitation Letter- Stroke Unit- Version  
2 (03/03/09)

Department of Psychological  
Services  
New Craigs  
6-16 Leachkin Road  
Inverness IV3 8NP  
Telephone 01463 704683  
Fax 01463 704686



Email: [jtodman@nhs.net](mailto:jtodman@nhs.net)

3rd March 2009

Study title: Investigating the Quality of Life of Stroke Survivors

Dear Sir or Madam,

You are invited to take part in a research study looking at some of the effects of suffering a stroke on the survivors' quality of life. The chief investigator is Jonathan Todman, a Trainee Clinical Psychologist in the Department of Psychological Services at NHS Highland. The study is sponsored by the University of Edinburgh.

I have enclosed an information sheet which aims to explain the study and a consent form where you can indicate that you are willing to be involved. Please read these carefully, and discuss them with others if you wish. It is entirely up to you to decide if you want to take part. If you would like to take part, please return the completed consent form using the enclosed stamped, addressed envelope. The contact details for Jonathan Todman are those at the top of this letter, and you are welcome to contact him with any questions you may have about participation in the project.

Thank you for your consideration.

Yours sincerely,

Dr Paul Findlay  
Stroke Unit Consultant

Invitation Letter- CHSS- Version  
2 (03/03/09)

CHSS Regional Office  
5 Mealmarket Close  
Inverness  
IV1 1HT  
Telephone 01463 701191  
Fax 01463 713699  
Email:  
margaret.somerville@chss.org.  
uk



3rd March 2009

Study title: Investigating the Quality of Life of Stroke Survivors

Dear Sir or Madam,

You are invited to take part in a research study looking at some of the effects of suffering a stroke on the survivors' quality of life. The chief investigator is Jonathan Todman, a Trainee Clinical Psychologist in the Department of Psychological Services at NHS Highland. The study is sponsored by the University of Edinburgh.

I have enclosed an information sheet which aims to explain the study and a consent form where you can indicate that you are willing to be involved. Please read these carefully, and if you wish discuss them with myself (contact details above) and with others. It is entirely up to you to decide if you want to take part. If you would like to take part, please return the completed consent form using the enclosed stamped, addressed envelope. The contact details for Jonathan Todman are given on the information sheet and you are welcome to contact him with any questions you may have about participation in the project.

Thank you for your consideration.

Yours sincerely,

Margaret Somerville  
Director of Advice and Support  
Chest, Heart and Stroke Scotland (Highland Regional Office)

## **APPENDIX 8**

### **Stroke survivor information sheet**

Information sheet- Version 3  
(09/03/09)

**Department of Psychological  
Services**  
New Craigs  
6-16 Leachkin Road  
Inverness IV3 8NP  
**Telephone 01463 704683**  
Fax 01463 704686



## INFORMATION SHEET FOR PARTICIPANTS

### **Study title: Investigating the Quality of Life of Stroke Survivors**

You are being invited to take part in a research study to investigate the quality of life of stroke survivors. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact the main researcher if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. Thank you for reading this.

#### **What is this study about?**

Stroke is the main cause of serious disability in later life, and is said to affect approximately 300 000 people a year in the UK. Patients and their families may experience a reduced quality of life following the stroke. However, it is possible the quality of life may get better or worse over time, and this may be noticed by their families. By comparing people who have recently had a stroke and their family members (Group A) with people who had a stroke some time ago and their family members (Group B), we hope to find out some of the differences between these groups. We hope that by finding out more about the difficulties that exist at different times after a stroke, and by looking at the views of the family as well as the stroke survivor, this will lead to better help being available to people who have suffered strokes and their families.

#### **Who is doing the research?**

The research is being carried out by Mr Jonathan Todman, Trainee Clinical Psychologist at the Department of Psychological Services, Inverness. The research is part of his qualification of Doctorate of Clinical Psychology at Edinburgh University. His work will be overseen by Dr Jim Law at the Department of Psychological Services, Inverness, and Dr Ken Laidlaw at the University of Edinburgh.

#### **Why have I been chosen?**

People who have had a stroke within the past five years are being asked to take part in the study, along with one family member who they nominate. The family member can be a spouse, son, daughter, brother, sister-in-law, etc. but must be over 18. Comparing people and families who have recently had a stroke with people who were in a similar position in the past few years will help us look at how things change over time after a stroke. You have been asked to take part because you fit these criteria.

#### **Do I have to take part?**

No. It is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part,

you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

**What will happen to me if I take part?**

You will be asked to nominate a member of your family who would also be willing to participate. You will be visited at a mutually convenient time by a member of the research team, or a meeting may be arranged at a local hospital if that is more convenient. At this meeting, you and your family member will be asked to separately complete a series of questionnaires. These relate to your current levels of quality of life, depression and anxiety, as well as some others to tell us more about your current situation. These should take around an hour of your time, and would take place on one occasion only. No further participation should be required, and the study will conclude by September 2009. If completing any of the questionnaires raises any issues you would like some help with, please contact the principle researcher (Jonathan Todman) who will be able to discuss these issues with you and, if you wish, will be able to suggest alternative sources of help.

**Will my responses be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. All of the information gathered will have your name removed so that you cannot be recognised. The only people with access to this information will be the principle researcher and his two supervisors.

**What are the possible benefits of taking part?**

There are no individual benefits for taking part in this study. However, it is possible that information obtained through this research may help improve services to benefit people who suffer a stroke and their families.

**What will happen to the results of this study?**

The results will be collected in a thesis submitted to the University of Edinburgh by the principle researcher. You will not be identified in this or in any publication that can be produced from this research. If you wish, you can receive a summary of results by informing the principle investigator.

**Who has reviewed this study?**

The study has been reviewed by the North of Scotland Research Ethics Committee.

**Who can I contact about the study?**

The principle researcher is Mr Jonathan Todman. If you have any questions about the study at all, please contact him at the address below:

Jonathan Todman  
Department of Psychological Services  
New Craigs  
6-16 Leachkin Road  
Inverness  
IV3 8NP  
**Telephone: 01463 704683**



## **APPENDIX 9**

### **Family member information sheet**

## INFORMATION SHEET FOR PARTICIPANTS

### **Study title: Investigating the Quality of Life of Stroke Survivors**

You are being invited to take part in a research study to investigate the quality of life of stroke survivors. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and discuss it with others if you wish. Please contact the main researcher if there is anything that is not clear or if you would like more information. Take time to decide whether you wish to take part. Thank you for reading this.

#### **What is this study about?**

Stroke is the main cause of serious disability in later life, and is said to affect approximately 300 000 people a year in the UK. Patients and their families may experience a reduced quality of life following the stroke. However, it is possible the quality of life may get better or worse over time, and this may be noticed by their families. By comparing people who have recently had a stroke and their family members (Group A) with people who had a stroke some time ago and their family members (Group B), we hope to find out some of the differences between these groups. We hope that by finding out more about the difficulties that exist at different times after a stroke, and by looking at the views of the family as well as the stroke survivor, this will lead to better help being available to people who have suffered strokes and their families.

#### **Who is doing the research?**

The research is being carried out by Mr Jonathan Todman, Trainee Clinical Psychologist at the Department of Psychological Services, Inverness. The research is part of his qualification of Doctorate of Clinical Psychology at Edinburgh University. His work will be overseen by Dr Jim Law at the Department of Psychological Services, Inverness, and Dr Ken Laidlaw at the University of Edinburgh.

#### **Why have I been chosen?**

People who have had a stroke within the past five years are being asked to take part in the study, along with one family member who they nominate. The family member can be a spouse, son, daughter, brother, sister-in-law, etc. but must be over 18. Comparing people and families who have recently had a stroke with people who were in a similar position in the past few years will help us look at how things change over time after a stroke. You have been asked to take part because you have been nominated by a stroke survivor as a family member who knows them well.

**Do I have to take part?**

No. It is up to you to decide whether to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you or your family member will receive.

**What will happen to me if I take part?**

You will be visited at a mutually convenient time by a member of the research team, or a meeting may be arranged at a local hospital if that is more convenient. You and your family member will be asked to separately complete a series of questionnaires. These relate to your family member's current levels of quality of life, depression and anxiety, as well as some others to tell us more about your current situation. These should take around an hour of your time, and would take place on one occasion only. No further participation should be required, and the study will conclude by September 2009. If completing any of the questionnaires raises any issues you would like some help with, please contact the principle researcher (Jonathan Todman) who will be able to discuss these issues with you and, if you wish, will be able to suggest alternative sources of help.

**Will my responses be kept confidential?**

All information which is collected about you during the course of the research will be kept strictly confidential. All of the information gathered will have your name removed so that you cannot be recognised. The only people with access to this information will be the principle researcher and his two supervisors.

**What are the possible benefits of taking part?**

There are no individual benefits for taking part in this study. However, it is possible that information obtained through this research may help improve services to benefit people who suffer a stroke and their families.

**What will happen to the results of this study?**

The results will be collected in a thesis submitted to the University of Edinburgh by the principle researcher. You will not be identified in this or in any publication that can be produced from this research. If you wish, you can receive a summary of results by informing the principle investigator.

**Who has reviewed this study?**

The study has been reviewed by the North of Scotland Research Ethics Committee.

**Who can I contact about the study?**

The principle researcher is Mr Jonathan Todman. If you have any questions about the study at all, please contact him at the address below:

Jonathan Todman  
Department of Psychological Services  
New Craigs  
6-16 Leachkin Road  
Inverness  
IV3 8NP  
Telephone: 01463 704683

## **APPENDIX 10**

### **Consent form**

Consent form- Version 2 (03/03/09)

**Department of Psychological  
Services**

New Craigs  
6-16 Leachkin Road  
Inverness IV3 8NP

**Telephone 01463 704683**

**Fax 01463 704686**



Participant Identification Number:

**CONSENT FORM**

**Title of Project:** Investigating the quality of life of stroke survivors at acute and chronic stages.

Main Researchers: Mr Jonathan Todman (Trainee Clinical Psychologist)

Dr Jim Law (Chartered Clinical Psychologist)

**Please initial in the box**

I have read and understand the information sheet dated 09/03/09 (Version 2) for the above study. I have had the opportunity to consider the information.

☐

I am aware that I can contact the principle researcher (Jonathan Todman) with any questions about the study

☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

☐

**I agree** to take part in the above study.

☐

\_\_\_\_\_  
Your Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Your Signature

(Please turn over)

If taking part in the study, please complete the following:

My phone number to arrange a suitable time and place to meet is:

---

**Please return this form using the stamped addressed envelope provided.**

.....

Researcher's name: Jonathan Todman

Date consent form received:

Researcher's signature:

## **APPENDIX 11a**

**Ethics Committee approval letter**

## **APPENDIX 11b**

**Research Governance approval letter**